EVALUATION OF BAYCREST CENTRE'S CARING FOR THE CAREGIVERS DEMONSTRATION PROJECT

VOLUME I

A Final Report to the
Ontario Ministry of Community and Social Services

The ARA Consulting Group Inc.
October 1990

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EXECUTIVE SUMMARY

In response to the increase in numbers of elderly individuals who remain in the community under the care of family members, and the concomitant problems/stresses faced by caregivers, Baycrest Centre for Geriatric Care developed a demonstration project geared toward the needs of caregivers. This demonstration project was designed to provide relatives of the elderly with counselling support, information and access to appropriate community services.

The demonstration project service model consisted of three components:

- assessment and counselling to caregiving families (and their elderly relatives where feasible);
- educational workshops on caregiving skills and other practical help; and
- mutual support groups for both primary caregivers and other family members.

These services were initially designed to increase the entire family's participation in the caregiver role, to improve the information and skills needed for effective care giving and prevent potential breakdown in the caregiving through early identification of family stressors.

Concurrent with the implementation of the demonstration project, an evaluation study was mounted in order to document and assess the implementation and the impact of the project.

The evaluation included two categories of research activity: process and outcome evaluation. Within these two categories of research, the transferability of the program was also assessed.

The process evaluation was designed to identify a number of client characteristics that could potentially affect service delivery and the outcomes of service. In addition, it was designed to determine whether the service delivery model was being implemented as planned and to identify implementation problems that arose during project operations. Finally, within the process evaluation framework, considerations for implementing the service model in other locations were addressed.

The outcome evaluation was designed to assess the impact of different service models on participating families and to identify the most cost-effective service model.

Clients were randomly assigned to one of three treatment conditions: Condition I - offering assessment/counselling plus referral; Condition II - offering assessment/counselling plus educational workshops plus referral; Condition III - offering assessment/counselling plus educational workshops plus mutual support groups plus referral.

Process and outcome evaluation data were gathered by project staff and by ARA researchers using a series of measures developed specifically for this program. Data were collected at five points in time: client intake, discharge and three follow-up points following discharge from the program.

Process data were analyzed periodically throughout the three years of service delivery. Results were fed back to the program operators so that decisions concerning client recruiting techniques and program refinement could be made as required. In addition, data were compared in order to identify process variations from project start-up to the final stages of project activity.

Outcome data were compared across the three treatment conditions and across time of entry into the program: during program start-up (Group I), during the middle year of operation (Group II), during the final year of service delivery (Group III).

The key findings and conclusions of the evaluation are reviewed below.

Client Characteristics

The majority of caregivers served by the program were primary caregivers who were daughters in their early sixties living with their elderly relatives and who were not employed outside the home. These caregivers were highly stressed in a number of areas and bore most of the caregiving responsibility with minimal involvement of other family members. They were caring for elderly relatives who were operating at fairly high levels cognitively and functionally, and had only recently entered the social service system regarding caregiver issues. The fact that these individuals were caring for fairly "intact" relatives, but were highly stressed early on in the caregiving process suggested that these clients represented an important sub-population of caregivers not previously identified as being in need of services. In general, areas in which clients needed assistance were: relief from caregiving responsibilities, planning for the future, emotional support, and to some extent, resolving conflicts with elderly relatives. Interventions related to caregiver skill development and increasing knowledge were not of primary importance in this caregiver sample.

Referrals to the Caregiver Project Services

Although referrals (largely self-referrals) to the program were appropriate, it was a constant struggle to keep up referral rates. At least one year of program operations was required to develop a consistent rate of referral. Public advertising and increasing awareness of the program within Baycrest itself augmented referrals to some extent. However, the fact that other assessment, counselling and referral services were available within Baycrest likely hindered referrals. In addition, other caregiver-specific programs became more widely available in the same catchment area, also contributing to referral difficulties. Therefore, coordination of caregiver services within sponsoring institutions and at the community and government levels will be essential as additional programs continue to emerge.

Since some of the Caregiver Project's services can be and were available in other programs for the elderly and since referrals were difficult to generate, it is suggested that such services should not operate as "stand-alone" programs but should be added to existing services (e.g. to adult day care or respite care programs, to Baycrest Centre's Central Intake Department).

Family Involvement in Caregiver Project Services

Clinicians were able to quickly assess client needs which corresponded to client-identified stressors and developed plans of care which were consistent with specified needs. Rapid and accurate assessments and intervention strategies are essential to a short-term treatment model. However, an important intervention goal in future services, which was not often included in clients' plans of care in this project, would be to encourage caregivers to include other family members and elderly relatives to share in the caregiving process. Lack of family participation in the Caregiver Project, few instances of change in family involvement in care as a result of the services offered, and the degree to which primary caregivers bore the majority of the caregiving responsibility, all support the conclusion that future interventions should focus on assisting caregivers in sharing the caregiving role.

Counselling, Mutual Support Group and Educational Services

Differential treatment impacts did not emerge from the three treatment conditions in this study. This finding suggests that future caregiver services should employ counselling interventions (the least costly treatment modality of the three offered) with additional group work (supportive and educational) on an as-needed basis.

The counselling aspect of service delivery tended to be constrained by the research effort's time limits. Many clients needed additional service which could not be provided within the allotted intervention/research time frame. Situational changes affecting caregivers' ability to provide care tended to emerge fairly soon after the intervention period. Therefore a short-term treatment model for caregivers needs to be flexible in the timing of its counselling interventions and should provide staffing resources to accommodate a series of brief interventions over a longer period of time.

If clients are to receive counselling services as well as group interventions in the form of mutual support groups and educational input, all interventions should be spread over a longer time period. More realistic time demands may decrease service dropout rates.

Since educational workshops and mutual support groups tended to overlap in content and format, and since educational input was not a critical issue for caregivers, future interventions should combine these types of groups in order to provide more cost-efficient service.

Although the support group component of the service was considered to be quite useful by client participants, contact amongst its members did not continue beyond the professionally-led sessions. It may be unreasonable to expect continuation of these groups because clients may not require additional sessions, they may not have the time to organize more groups and/or may prefer professionally-led sessions.

Referrals to Other Services

A small group of clients did experience impediments in obtaining community resources which had been suggested by project staff. Therefore, it is suggested that the relevance and

lack of availability of particular services should be discussed with clients during the discharge and referral process.

Indicators of Program Impact

Given the relatively high level of functioning of caregivers, families and elderly relatives, outcome measures related to changes in family conflict, cooperation, feelings of competence, knowledge/skill levels and elderly relatives' status re institutionalization were of low relevance. Furthermore, expected outcomes related to reduction in psychological stress levels may have been too ambitious for some clients participating in a short-term treatment model. Feelings of support and ability to cope may be other useful indicators of impact in future programs.

Suggestions for Future Research

Since the evaluation effort tended to restrict the natural flow of the Caregiver Project's intervention process, a number of improvements for future research endeavours were suggested. Suggestions included:

- the elimination of random assignment procedures;
- the inclusion of data from "project dropouts" in data analysis; and
- delaying evaluation until the program has been operating for a year, so that evaluation plans can be based on a realistic understanding of the intervention process.

Recommendations for ongoing process evaluation/monitoring of caregiver services were also provided.

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1.0 STUDY BACKGROUND

1.1 Baycrest Centre for Geriatric Care

Baycrest Centre for Geriatric Care comprises five facilities that together provide a wide range of services to the elderly. The longest established of these facilities is the Jewish Home for the Aged founded in 1918. Baycrest Hospital opened in 1954; Baycrest Day Care Service began in 1959; and Baycrest Terrace and Joseph E. and Minnie Wagman Centre were officially opened in 1976.

The five facilities are linked by a common aim, formally set out in Baycrest Centre's Mission Statement:

- to provide leadership in the delivery and development of services of the highest quality to the elderly and chronically ill, within a framework of financially responsible administration.

This goal is to be accomplished through the provision of services to individuals requiring institutional care, participation in the development and/or provision of services as an alternative to institutional care, and research and education in aging to find better ways to meet the needs of the aged population. Baycrest Centre is a non-profit organization with a 36-person Board of Directors, all of whom are volunteers.

The Central Intake Department in Baycrest Centre plays a crucial role in matching institutional and day care services to the needs of elderly people in the community. Essentially, it provides a counselling and referral service to elderly individuals and their families who are seriously considering institutional or day care services. Three main objectives guide the work of the Central Intake Department:

- to provide services to elderly Jewish people in the greater Toronto area who require institutional care;
- to participate in the development of and provide leadership for a comprehensive range of services to the Toronto community as a whole and to prevent unnecessary institutionalization; and
- to provide help to the families of older people (non-sectarian) who are seeking to support their relative in the community.

1.2 Need for the Caring for the Caregivers Project

Prior to 1987, the Central Intake Department of the Baycrest Centre witnessed a dramatic increase in applicants for service who required heavy nursing care and/or suffered from severe cognitive impairments. These elderly individuals were typically too sick or needed too much care to be admitted to nursing homes or homes for the aged, but were unable to

gain admission to chronic care hospitals because of lengthy waiting lists. Therefore, many of these individuals remained in the community, being cared for by their families.

The burden on families of caring for a dependent elderly relative in need of extensive care and supervision can be enormous. Not only are there demands on the primary caretaker (who is typically an older woman who may herself have significant health care and support needs) but these demands can also result in stresses among members of the care-giving family. The task of providing care for a dependent elderly parent is further complicated by the limited availability or families' limited awareness of services for the elderly and for their caregivers.

In response to the increase in the numbers of elderly individuals who remain in the community under the care of family members, and the concomitant problems/stresses faced by caregivers, Baycrest Centre for Geriatric Care developed a demonstration project geared toward the needs of caregivers. The project was funded by the National Welfare Grants Directorate, Health and Welfare Canada. This demonstration project, "Caring for the Caregivers" was designed to provide relatives of the elderly with counselling, support, information and access to appropriate community services.

1.3 Project Service Model

The demonstration project service model had three components:

- assessment and counselling to caregiving families (and their elderly relatives where feasible);
- educational workshops on caregiving skills and other practical help; and
- mutual support groups for both primary caregivers and other family members.

These services were initially designed to increase the entire family's participation in the caregiver role, to improve both the information and skills needed for effective caregiving, to direct clients to resources outside the caregiving family, and to prevent potential breakdown in the caregiver role through early identification of family stressors.

Participants in this project were expected to emerge from two sources: families who contacted Baycrest Centre's Central Intake department directly, seeking services from one of the Baycrest facilities; and families who were referred by agencies within the community. It was also initially anticipated that the target population would consist of four sub-groups reflecting the general condition and circumstances of the elderly relative in family care:

- families of elderly people who were physically impaired and remained in the community because there was no alternative. Included are elderly persons who had been refused admission to a nursing home or home for the aged because of needs for heavy nursing care but whose

needs were not yet sufficiently severe to permit admission to a chronic hospital;

- families of elderly people who were physically impaired, on a waiting list for long-term placement, and in the meantime, were being cared for at home;
- families of cognitively impaired elderly people who needed 24 hour supervision and/or nursing care, or who were awaiting placement in an institution; and
- families of frail elderly people who were not seeking admission to an institution but who were dependent on the support of their families.

Initially, 200 families were expected to be admitted to the program. In order to participate in the project, elderly relatives had to be older than 60 years of age, living in the community, and not at risk of institutional placement within six months of referral to the project. Availability of an identifiable family/surrogate caregiver who spoke English was also a requirement for participation in the Caregiver Project. As well, families had to understand the purposes and time commitments required for the project and had to consent to involvement in the evaluation as a precondition for participation.

The project began in February 1987 and continued for three and a half years, with the final months designated for completing follow-up evaluations and an evaluation report. Participants were expected to enter the program in groups of approximately 22 throughout the 30 months of program operation. Each treatment wave was to consist of 22 participants. A total of nine treatment waves were planned over the 30 month course of the project. Since many of the treatment waves did not reach capacity (i.e. they did not have 22 participants), a tenth wave was added prior to project termination to augment the number of families completing the program.

1.4 Project Evaluation

Concurrent with the implementation of the demonstration project, an evaluation study funded by the Ontario Ministry of Community and Social Services was mounted in order to document and assess both the implementation and the impact of the project. The general goals of the evaluation were:

- to determine whether the project was successful in meeting its stated objectives; and
- to determine the potential transferability of the service model to other settings.

Specific objectives of the evaluation included:

- documentation of characteristics of families served by the project;
- documentation of activities of project staff and services provided;
- examination of outcomes achieved by the project; and
- determination of costs.

2.0 GENERAL EVALUATION DESIGN

The design of the evaluation included two categories of research activity: process and outcome evaluation. Within these two categories of research, the transferability of the program was also assessed.

Initial design plans were to examine the processes, outcomes and transferability of the demonstration project for three treatment conditions and two types of referral sources. Subjects were to be randomly assigned to one of the three treatment conditions.

Some of the initial design plans required modification early on in the lifetime of the project. Two types of referral sources were to be examined (Baycrest Central Intake and Community referrals). However, there were not enough referrals from these two sources to permit valid statistical comparisons between and across all treatment conditions. Therefore, Referral Source did not serve as an independent factor in the evaluation design, but rather was considered as one of a number of descriptor variables. In addition, somewhat different designs were warranted in each of the process and outcome evaluation categories. Therefore, research designs in each of these categories are outlined in separate sections below. Each type of evaluation is described in relation to the general research questions that were addressed, associated data sources and data analysis frameworks.

2.1 Process Evaluation

The process evaluation was designed to identify a number of client characteristics that could potentially affect service delivery and the outcomes of service. In addition, it was designed to determine whether the service delivery model was being implemented as planned and to identify implementation problems that arose during project operations. Finally, issues which would be relevant for the implementation of the service model developed for this project were considered.

The process evaluation addressed the following types of issues regarding client characteristics:

- demographics;
- family relationships/dynamics;
- family resources and strengths;

- family stressors;
- family needs;
- the family's understanding of the elderly person's condition;
- the family's caregiving skills and comfort/competence with the caregiving role;
- the family's awareness and use of community resources;
- the level of impairment/disability manifested by the elderly person; and
- the perceived need for institutionalization of the elderly person.

In addition, the process evaluation addressed service delivery issues in the following areas:

- referral;
- intake;
- assessment/counselling;
- educational workshops;
- support groups; and
- discharge (including community referral).

Finally the process evaluation addressed the following program transferability issues:

- the amount of time clients can realistically be expected to spend in service components;
- the amount of staff time necessary to administer the project and deliver services;
- the necessary organizational structures and resources needed for program delivery;
- the most efficient and effective methods of delivering the various service components; and
- the special qualities of the setting which could be critical for program delivery.

Data regarding client characteristics and the characteristics, quality and quantity of service delivery, were drawn from several sources which included:

- primary caregiver intake questionnaires;
- "other family member" intake questionnaires;

- the Family Assessment Measure (FAM), a standardized questionnaire tapping family dynamics;
- clinical recording systems that were developed for this project, in close collaboration with program staff; and
- general program information systems that were developed specifically for this project, in close collaboration with program staff.

Process evaluation data were analyzed as each treatment wave was completed and results were fed back to the program operators so that decisions concerning client recruiting techniques and program refinement could be made as required.

In addition, the process data were analyzed in clusters of three treatment waves representing the start-up, mid-point and final stages of program operations. Data from waves one to three (Group I), four to six (Group II) and seven to ten (Group III) were compared in order to identify process variations over time. It was important to assess these group variations over time because of their potential to differentially affect project outcomes.

2.2 Outcome Evaluation

The outcome evaluation was designed to assess the impact of the program on participating families and to identify the most cost-effective service model in three treatment conditions:

Treatment Condition	Referral	Assessment/ Counselling	Educational Workshops	Mutual Support
I	✓	✓		
II	✓	✓	✓	
III	✓	✓	✓	✓

More specifically, the outcome evaluation addressed the following types of research issues:

- changes in family dynamics;
- changes in family involvement in the caregiving role;
- impact of participation on knowledge about the condition of the elderly person;
- impact of participation on caregiving skills and comfort/competence with the caregiving role;
- impact of participation on knowledge and use of community resources;

- changes in the family's ability to maintain the elderly person in the community;
- achievement of family-specific service goals identified in plans of care;
- development of mutual support groups into self-help groups following discharge from the program;
- client satisfaction with the Caregiver Project; and
- the relationship between program costs and specific outcomes.

Data regarding program outcomes were obtained from the following sources:

- primary caregiver intake, and Follow-up I and II questionnaires/interviews;
- "other family member's" intake and Follow-up I and II questionnaires/interviews;
- the Family Assessment Measure (FAM) completed by families at intake and Follow-up I points in time;
- clinical recording systems used at intake, discharge and follow-up III time periods; and
- general program information systems developed specifically for this project.

Since some data were collected from a variety of sources, such as the primary caregiver and clinical staff, impacts of some variables could be assessed from different perspectives.

In general, outcome-related information was compared across treatment conditions I to III and across groups I to III. Treatment condition and group data were analyzed in terms of descriptive statistics (frequencies and percentages) or analyses of variance (ANOVA).

Where ANOVAs were employed, difference scores between specific measurement points (i.e. Intake to Discharge, Intake to Follow-up I, Intake to Follow-up II, Follow-up I to Follow-up II, Intake to Follow-up III and Discharge to Follow-up III) served as dependent measures. It should be noted that some outcome data were collected at all five measurement time periods (Intake, Discharge, Follow-up I, II, and III) while other data were collected at only two or three points in time. Therefore ANOVA comparisons varied in terms of the difference scores employed as dependent measures.

Having described the general evaluation design, the reader is referred to Appendix A for a listing of the specific research questions in each of the process, outcome and transferability areas and the specific data sources and measurement time periods associated with each of these research questions. This listing also identifies the locations in the text of the report where findings related to each research question are addressed.

3.0 METHODOLOGY/PROCEDURES

3.1 Introduction

In presenting the procedures of the Caregiver Project evaluation, the data collection instruments that were employed will be identified. Each of the instruments, along with detailed descriptions of associated administration procedures, can be found in Volume II of this report.

As noted earlier, families were admitted to the program in a series of ten separate treatment waves with a maximum of 22 admissions permitted per wave. In any treatment wave, two out of three possible treatment conditions were offered. The A.R.A. Group's consultants determined which two treatment conditions were to be offered in each of the first nine waves, using random assignment procedures prior to project start-up. The treatment conditions offered in the extra treatment wave (wave 10) were not determined by random assignment but were specifically selected to augment client numbers in conditions II and III. Treatment Condition I was offered six times during the course of the project, while Conditions II and III were offered seven times each. Families were randomly assigned to a treatment condition at the time of their admission to the project.

Baycrest Centre's project staff (one full-time social worker, who was the Project Director, and one half-time social worker) were responsible for all data collection up until a family's discharge from the project. Following discharge, A.R.A.'s researcher was responsible for most of the follow-up data collection with families, although Baycrest Centre's social workers did complete a final follow-up interview approximately six-months post discharge. Baycrest Centre project staff were responsible for collecting all data pertaining to program operations as well. The chart below highlights persons responsible for data gathering at various points throughout the project.

	DATA COLLECTION POINTS				
Persons Responsible	Intake	Discharge	Follow-up I	Follow-up II	Follow-up III
Baycrest Staff	●	●			●
ARA Researcher			●	●	

3.2 Intake/Assessment Procedures

Each treatment wave began with a time-limited intake period, where referrals to the program were accepted on a first-come first-served basis. Since most treatment waves did not reach a complement of 22 referred families, intake procedures terminated at a predetermined point in time and treatment proceeded without the anticipated number of participating families.

When a referral was made to the Caregiver Project, the Project Director completed an Enquiry Form (see Volume II, item 6) which provided basic demographic data, referral data and criteria for admission to the project. If the family met the admission criteria, an intake/assessment interview was arranged. All involved family members were asked to attend if possible.

Once the intake/assessment interview was arranged, project staff phoned A.R.A. to obtain a randomly assigned treatment condition for the family. The reader is referred to the Random Assignment form located in Volume II, item 5, which provides an example of family assignments to the particular treatment conditions offered in waves 1 to 3.

When families arrived for the intake/assessment interview, the nature of the Caregiver Project and the need to participate in the evaluation was fully explained by project social work staff. Families were informed about the treatment condition to which they had been randomly assigned, and were asked to sign a consent form indicating that they agreed to and understood the requirements of the project (see Volume II, item 8, for a copy of the Informed Consent form).

As part of the intake/assessment interview, the primary caregiver was clearly identified. The primary caregiver was considered to be the person who was living with the elderly relative, or if not living with their relative, the person who was taking primary responsibility for the care of the relative. If the primary caregiver still could not be identified based on these two criteria, then the individual who first contacted the Caregiver Project and indicated the need for assistance was considered to be the primary caregiver.

The identified caregiver was asked to complete a Primary Caregiver Intake Questionnaire (see Volume II, item 9). This questionnaire addressed a number of issues relevant to the outcome evaluation and served as a baseline measure of factors such as primary caregiver stressors, family cooperation/conflict in caring for the elderly relative, etc. Other family members present at the intake/assessment interview were asked to complete a similar Intake Questionnaire (see Volume II, item 6). The primary caregiver and other family members completed the Family Assessment Measure (FAM), a standardized paper and pencil measure designed to assess family functioning along a number of dimensions (see Volume II, item 12). The FAM was intended to serve as an additional baseline measure for determining project outcomes for participating families.

Family members received the Intake Questionnaires and the FAM at any one of the first three sessions. If a family member did not appear until after the third session, they did not complete intake information.

Following the initial interview, the social worker completed a write-up of the session using the Assessment Interview format, developed as a clinical recording and research tool specifically for this project (see Volume II, item 11). Information in this instrument provided demographic and family background data as well as baseline data for use in determining project outcomes. These data, coupled with primary caregiver and other family member questionnaires, were designed to provide information from a variety of perspectives.

It should be noted that if it was clear at the beginning of an intake/assessment interview that the family did not wish to participate in the project, or was inappropriate for the service, family questionnaires and the assessment interview write-up were not completed.

Once the intake/assessment interview was finished, the social worker filled out a Face Sheet which was inserted in the family's file and updated regularly. The Face Sheet provided summary data about the family's status in the program (admitted, discharged, screened out after interview, dropped out of project, etc.). It also provided information about referrals to additional services that were made during or following the treatment period (see Volume II, item 7). These data were used for process evaluation purposes.

3.3 Treatment Phase Procedures

Following intake/assessment procedures, families entered the formal treatment phase of the program. Counselling sessions were conducted by Baycrest project staff. The number of counselling sessions per family varied depending upon individual need and willingness to participate. Similarly, the presence of family members at counselling sessions varied according to need and readiness to participate. Families in all three treatment conditions received counselling.

During counselling sessions, the social worker developed a Plan of Care with the family (see Volume II, item 13). The plan stated specific treatment objectives which were based on needs identified during intake/assessment. Additional objectives and strategies for achieving these objectives were added during the course of the program. Progress toward meeting objectives was also recorded throughout and/or following the treatment period. Data from the Plan of Care were relevant to the evaluation of treatment processes, program transferability and outcomes.

Those families which were randomly assigned to treatment conditions offering educational workshops (Condition II and III) attended two workshops, each lasting approximately one and a half hours. Lecture or video presentations were followed by group discussions. Workshop presentations were designed to focus on: 1) the ageing process; 2) cognitive impairments in the elderly and 3) ways of adapting the home to accommodate physical and cognitive impairments. Following each workshop, project staff completed a Meeting Sheet (see Volume II, item 4) identifying numbers attending the workshop, the focus of the presentation and the content of group discussion. This information provided data relevant to the process evaluation and transferability assessment of the Caregiver Project.

As well as counselling and education, families which were assigned to the treatment condition offering mutual support groups (Condition III) attended a total of six support group sessions, each lasting approximately one and a half hours. Support groups were led by project social work staff, however, the specific content of these sessions was left unstructured so that the group itself could determine the direction of its discussions. Following each session, project staff completed a Meeting Sheet form (Volume II, item 4) identifying numbers attending the support group and topics addressed in the session. These data were relevant for the process evaluation and transferability assessment.

3.4 Discharge and Follow-up Procedures

When the formal treatment portion of each condition in each wave was complete, social work staff conducted a discharge interview with individual families. At this time, families were also given a letter (see Volume II, item 15) reminding them that they were participating in a research project and that A.R.A.'s researcher would be contacting them to gather some additional information about their participation in the project.

Following the discharge interview, the social worker completed a write-up of the session using the Discharge Interview format (see Volume II, item 14) which was developed as a clinical recording and research tool for this project. Information contained in this document parallelled data collected at intake and served as one of the measures of project outcome. At this time, project staff also completed information contained in the Plan of Care (described earlier), indicating the extent to which specific treatment objectives were achieved. These data also served as measures of project outcome from the project staff's perspective.

A.R.A.'s research assistant reviewed Baycrest files as they were completed and arranged and conducted a follow-up interview (Follow-up I, usually in the primary caregiver's home) as soon as possible after the family's formal discharge from the Baycrest program. If a family could not be reached within six weeks of receipt of the completed Baycrest file, they were considered to have missing data for the first follow-up period, but were contacted again at the second follow-up time. Even if clients were contacted, and initial follow-up interviews were arranged, cancellations and re-scheduling often occurred. Therefore, Follow-up I interviews took place anywhere from three to twenty weeks post discharge from the Caregiver Program.

At the Follow-up I interview, the primary caregiver and any other family members in attendance were asked to respond to questions contained in Follow-up I Questionnaires. These questions parallelled those addressed in Intake Questionnaires (e.g. stressors, family conflict/cooperation) and also focused on satisfaction with the Baycrest program and various components of the treatment model. The Family Assessment Measure (described earlier) was also completed by all members of the family in attendance at the A.R.A. Follow-up I interview. All of these measures (primary caregiver and family member Follow-up I Questionnaires, FAM) were relevant to the assessment of project outcomes.

It should be noted that if a family dropped out of the Baycrest program prior to completion of the services offered in the treatment condition to which they were assigned, A.R.A. did not conduct a Follow-up I interview. Families assigned to the counselling condition were considered as program dropouts if they attended less than two counselling sessions[1]. Families assigned to the counselling and educational workshop condition were considered

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[1] For purposes of clarity, intake and discharge interviews have been discussed separately from formal intervention procedures. In fact, they were considered to be an integral part of the intervention process in that a good deal of counselling was provided during these interviews. Therefore, intake and discharge interviews were counted as counselling sessions and figured into the determination of program dropouts. They were also included as counselling sessions in other process analyses.

to be dropouts if they failed to attend an educational workshop as well as two counselling sessions (at least one family member was required to attend one workshop). Families assigned to Condition III had to attend at least one educational workshop, three support groups as well as two counselling sessions in order to be considered part of the project (at least one family member had to be present at each of these sessions).

Approximately three months after the A.R.A. Follow-up I interview, a second follow-up interview was conducted with the primary caregiver via telephone. Once again, if a caregiver could not be reached to schedule an interview within six weeks of the designated Follow-up II time period, the case was considered to have missing data and no further attempts were made to arrange a second follow-up interview. A.R.A.'s researcher conducted these interviews using a Follow-up II Questionnaire (see item 18, Volume II). This questionnaire provided further outcome data.

Six months following Baycrest's discharge interview, a third follow-up interview with the family was conducted by project social workers. At this time, a Follow-up III Interview Protocol was completed by Baycrest staff (see item 19, Volume II), providing additional outcome data.

Initial evaluation plans called for a fourth follow-up interview to be conducted by the A.R.A. researcher three months after Baycrest's Follow-up III interview. This data collection point was eliminated due to difficulties in re-contacting clients and because of the number of non-program-related events in clients' lives that would confound Follow-up IV results.

If an elderly relative died during the intervention period, a discharge interview was conducted but further follow-up interviews were eliminated. If an elderly relative died between follow-up periods, the next scheduled follow-up interview was conducted while the remaining interviews were eliminated.

3.5 Miscellaneous Procedures

There were a number of evaluation procedures which were not associated with particular phases of treatment waves, but rather occurred on an ongoing basis throughout each wave. These procedures are briefly outlined below.

Social work staff completed a Master Schedule for each client (see Volume II, item 3). This schedule recorded individual families' participation time in each part of the treatment model (i.e., intake/assessment interview, counselling sessions, educational workshops, if applicable, mutual support groups, if applicable, and discharge interview). It also identified which family members participated in particular treatment components. The Master Schedule, therefore, provided an indication of the amount of time social workers spent in direct family contact and the degree to which families became involved in the project. Data from this schedule were relevant to process evaluation and transferability issues.

Project staff also completed an Administrative Activity Timesheet on a daily basis (Item 2, Volume II). This time sheet provided data concerning the number of hours spent in a variety of administrative activities (general project administration, educational workshop administration, support group administration and research/evaluation activity). In general, this instrument was designed to indicate the amount of time needed to mount a program

of this nature and to provide information relevant to process and transferability evaluation issues.

4.0 PROCESS EVALUATION FINDINGS

4.1 Introduction

To briefly reiterate earlier portions of this report, process data were collected during the three years of project service delivery using the following instruments (items referred to are found in Volume II):

- program Enquiry Sheet (item 6);
- social worker Intake Assessment Interview (item 11);
- client Face Sheet (item 7);
- Primary Caregiver Intake Questionnaire (item 9);
- Family Member Intake Questionnaire (item 10);
- the Family Assessment Measure (FAM) (item 12);
- client Plans of Care (item 13);
- educational workshop and self-help group Meeting Sheets (item 4);
- program Master Schedule (item 3); and
- staff Administrative Activity Time Sheet (item 2).

Data from Group I were aggregated for year one of service delivery. Data from Group II were aggregated and represented year two of project operations. Finally, process data from Group III were aggregated for the third year of service.

The data were analyzed using descriptive statistics (frequencies, percentages, means and medians) and results are presented in Tables 1-23 (Appendix B). Tabular presentations are organized into the following categories of information:

- sample disposition;
- referral data;
- elderly relative data;
- primary caregiver data;
- family data;
- service delivery data; and
- miscellaneous data.

4.2 Cautions in Data Interpretation

A number of cautionary notes are warranted in interpreting specific aspects of the process data.

First, with regard to information about elderly relatives' level of functioning (Appendix B, Table 4), these data were obtained without face-to-face contact with the elderly person in more than 50% of the cases. That is, social workers rated levels of physical and cognitive impairment, based largely on information provided by family members at the intake/assessment interview. In Group I, elderly relatives rarely participated directly in the project. In Group II, under half (40%) of elderly relatives participated in at least one counselling session. In Group III approximately one half of elderly relatives participated in counselling sessions (see Appendix B, Table 16). Therefore, the accuracy of the data regarding level of functioning may be questionable. However, they may provide useful information regarding families' *perceptions* of their relatives' abilities.

A second cautionary note is warranted with regard to process data on family members other than the primary caregiver. In Groups I and II, respectively, only half of admitted families had members who completed Intake Questionnaires, which provided the principal vehicle for collection of information concerning family characteristics (see Appendix B, Table 8). In Group III an even lower percentage of families had members completing intake information (32%) (Appendix B, Table 8). Therefore the Family Data section of Appendix B (Tables 8-12) may not be representative of the total sample of families and will not be discussed in detail.

One final caution regarding the interpretation of process data concerns the Family Assessment Measure (FAM), which measured family functioning from the primary caregiver and other family member points of view (Table 11, Appendix B). In Groups I and II a sizeable proportion of the questionnaires completed by both primary caregivers and other family members were invalidated because of high scores on exclusionary scales (e.g. Social Desirability). The remaining data may not be highly representative of program participants in these groups. FAM data for Group III may be more representative, since valid measures were available from 72% of primary caregivers and family members. However, it should be noted that although 72% of family members in Group III provided valid questionnaires, only 32% of admitted families were represented by these data. In summary, FAM data should be viewed with caution and will not be discussed extensively in this report.

Bearing these cautionary notes in mind, interpretations of process-related data for all three groups follow.

4.3 Interpretations Re: Sample Disposition

For the purposes of this report, sample disposition refers to rates of referral, admission and participation in the project as a whole.

Data from Appendix B, Table 1, indicate an increase in referrals to the project from Group I to Group II (66 and 96 referrals, respectively). On average, there were 32 referrals per wave in Groups II and III respectively, indicating that referral rates remained stable during

the middle and latter phases of the project. These data suggest that at least one year of program operations are required to develop a consistent rate of referral.

Advertising efforts may have served to increase referral rates, as indicated by the proportion of referrals in Group II who heard about the program from media sources (38% compared to 19% in Group I, see Appendix B, Table 3). Increased awareness of the program within Baycrest itself seems to have maintained the consistent rate of referrals in Group III, as indicated by the proportion of referrals who heard about the program from Baycrest professionals (53%, Table 3).

While advertising and increased awareness of the program within Baycrest may have augmented referrals somewhat, anecdotal remarks from the Project Director over the three-year course of service delivery identified constant difficulties in obtaining enough referrals for the project. Since assessment, counselling and referral services were available through other programs both within and outside Baycrest Centre, the Caregiver Project may have lost referrals to other programs. The fact that several other programs specifically designed for caregivers were in operation in the same catchment area simultaneously may also account for some of the referral difficulties. Community professionals were rarely information sources for Caregiver Project referrals in the last two groups (16% and 15% respectively: Appendix B, Table 3), reinforcing the conclusion that similar programs were hindering program referrals.

These findings and interpretations speak to the need for coordination of caregiver services within the sponsoring institution and at community and government levels. For example, it would be more efficient to add caregiver services to an existing program which already deals with the desired client population. That is, the service model should not operate as a "stand-alone" program. In Baycrest Centre's case, it may be feasible to have Intake Department workers conduct assessments, develop treatment plans and provide counselling with specific caregiver issues in mind. Mutual support groups and educational workshops could be provided when sufficient numbers of participants are available on an as-needed basis. These activities would serve as additional components to existing Intake Department services. Duplications in activities could then be avoided. In other settings, this kind of service could be added to existing adult day care or respite care programs.

Data pertaining to actual referral sources were fairly consistent across the three groups in that the majority of referrals came directly from family members themselves (Table 2). In Group I, 65% of all referrals and 76% of referrals from admitted families were self-referrals. In Group II, 71% of all referrals and 80% of admitted referrals were self-referrals and in Group III these rates of self-referrals were 62% and 71%, respectively. In Groups I and II, only a small proportion of families were involved with community resources (36%, 43%: Appendix B, Table 20a) when entering the Baycrest Centre program, explaining why self referrals to the Caregiver Project were more common than community agency referrals. The Baycrest Centre may be these families' initial point of professional contact in seeking assistance with caregiving issues.

In Group III, a higher proportion (76%) of families were already involved with other community resources when entering the Caregiver Program (Appendix B, Table 20a). It is likely that workers in other Baycrest Centre programs suggested that the family make the

initial contact with the Caregiver Project, accounting for the high rate of self-referrals in Group III. These findings suggest that families in Group III had been dealing with caregiving issues for a longer period of time than those in Groups I and II because they had already been involved with other types of assistance concerning their elderly relative. In summary then, self-referrals to the project were high. Clients referred in Groups I and II were likely just beginning to deal with caregiving issues, while clients referred in Group III may have been dealing with these issues for a longer time period.

Project admission data were consistent across all wave groups in that the majority of referrals were in fact admitted to the program (Group I-64%, Group II-60%, Group III-55%: Appendix B, Table 1). In other words, families referred to the project were appropriately referred. For those referrals who were screened out of the project, it appears that it was the caregiver, not the program staff who made the "non-participation" decision (Table 1). It is possible that caregivers screened themselves out of the program when they found out they would be assigned to a particular form of treatment (as a result of the evaluation project), which they may not have felt that they needed in the first place.

Once families were admitted to the project, the majority of them did complete the program. These data were consistent across Groups I-III (74%, 71%, 70%: Appendix B, Table 1). While program completion rates were acceptable, a fairly high dropout rate in all groups was evident (26%, 29%, 30%: Appendix B, Table 1). It is highly likely that the time commitments required to complete the program account for the majority of dropouts. Significant dropout rates placed additional pressure on project staff to increase referrals. As noted above, augmenting referrals was a constant struggle for the project.

These findings suggest that future caregiver-oriented services should place more realistic time demands on clients, or at least spread the intervention over a longer time period. This approach may curtail client dropouts from service.

To summarize, interpretations regarding sample disposition/referral data across all three groups suggest:

- that at least one year was required to develop consistent referral rates;
- public advertising and increasing awareness of the program within the service delivery agency itself served to augment referrals to some extent;
- that other programs offering assessment, counselling and referral services may have drawn away referrals from the project;
- that caregiver-specific programs in the same catchment area may have decreased referrals from community professionals;
- that there is a need for coordination of caregiver services within the sponsoring institution and at the community and government levels;

- that caregiver services should not operate as a "stand-alone" program, but should be added to existing services for the elderly.
- that for many self-referred clients, Baycrest Centre was likely the initial point of professional contact regarding assistance with caregiving issues;
- that referrals to the project were appropriate;
- that caregivers (not program staff) screened themselves out of the program, perhaps due to the treatment constraints placed on them by the research effort; and
- that client dropout rates were fairly high due to treatment time requirements; these could be reduced with more realistic time demands spread over a longer intervention period.

4.4 Interpretations Re: Elderly Relative Data

Characteristics of elderly relatives such as age (approximately 80 years), level of functional and cognitive impairment (slight), and past hospitalization (relatively infrequent), were consistent across Groups I, II, and III (Appendix B, Table 4). However, the ratio of male to female relatives differed across groups. In Group I, half of the relatives receiving care were female, while half were male. In Groups II and III the male to female ratio was approximately 1:2. Therefore, in the majority of cases male to female ratios were in line with what one would expect in a sample of elderly persons and the unusual findings from Group I were likely due to chance.

The data in Table 4 also indicate that the perceived need for institutionalization from both the caregiver and social worker viewpoints, was not high in any of the three groups (31%-Group I, 9%-Group II, 20%-Group III). It is interesting to note however, that in Group II there was a particularly low need for institutionalization relative to the other two groups. It may be that spouse caregivers, who were more prevalent in Group II (see Appendix B, Table 5), were less inclined to feel their relative required institutionalization than the daughter/son caregivers which were prevalent in Groups I and III.

Taken together, the data across all groups indicate that elderly relatives were functioning fairly well and did not need to be considered for institutionalization in the very near future (Appendix B, Table 4). Therefore, the Caregiver Project did not attract the population it expected to serve. As described in the "Study Background" section of this report (see page 3), families of physically and cognitively impaired individuals who could not gain admission to institutions were the expected client group for this service. Clearly caregivers attracted to this project were not caring for these types of relatives. It is suggested that it may be unrealistic to expect families with severely impaired relatives to invest time and energy in this type of program. However, it is also suggested that even though their elderly relatives were functioning well, these caregivers were experiencing enough stress to seek assistance

(see Appendix B, Table 6). Although the project did not seem to be serving the population it expected to serve, it was likely addressing the needs of an important sub-population of caregivers. This group probably has not been identified in the past as requiring services.

In summary, the findings and interpretations of the data for elderly relatives suggest:

- that the male:female ratios in Group I were unusual and did not reflect the sample as a whole;
- that characteristics of elderly relatives did not reflect the expected population for this project; and
- that the Caregiver Program was serving an important sub-population of caregivers who have not been identified in the past as being in need of services.

4.5 Interpretations Re: Primary Caregiver and Family Characteristics

Data across groups generally indicated that the majority of primary caregivers participating in the project were adult daughters in their early sixties, living with the elderly parent and not working outside of the home (Appendix B, Table 5). While the majority of caregivers did not work outside the home, a significant proportion were involved in outside employment (Group I-53%, Group II-39%, Group III-40%: Appendix B, Table 5).

There were some differences between groups on the characteristics cited above (see Appendix B, Table 5). Group I had very few male caregivers (5% compared to 26% in Group II and 21% in Group III), fewer caregivers at home full time (43% compared to 65% in Group II and 60% in Group III), and fewer caregivers living with elderly relatives (51% compared to 73% and 62% respectively). Group II showed a more even split between spouse and child caregivers than in the other two groups (48%:50% in Group II, 34%:66% in Group I, 31%:69% in Group III).

Primary caregivers were fairly stressed about a number of issues (Appendix B, Table 6). While the same issues were stressful across groups, fewer caregivers in Group III were stressed about the health of their relative, their relative's future, their own future, and the physical demands of caregiving, than in the other two groups. In addition Group III's overall ratings of stress were lower (moderate stress compared to major stress) and caregiving was seen as more rewarding than in Groups I and II (Appendix B, Table 6). However, a high degree of stress was characteristic of the majority of project participants, and the greater the stress level, the less rewarding was their perception of the caregiving role.

In general, caregivers perceived that there was little conflict between family members in caring for their elderly relative. Family conflict was identified as a stressor by 42% of Group I, 38% of Group II and 37% of Group III (Appendix B, Table 6). In addition, an average rating of 3.8 on a 5-point scale (i.e. not much conflict) emerged across all groups when asked to rate the overall level of family conflict in caring for their elderly relatives (Appendix B, Table 11). Caregivers indicated that there was some cooperation (an average rating of approximately 3.2 on a 5-point scale) among family members in providing care

(Appendix B, Table 11). Finally, family members did tend to be consulted regarding decisions about elderly relatives (44% in Group I, 46% in Group II, 49% in Group III, Appendix B, Table 12). These findings were consistent across all groups.

Although primary caregivers seemed to feel that a moderate amount of support was available in caring for their relative, other data lead one to question whether family support was available even to that degree. For instance, there were no tasks which more than 50% of caregivers felt were shared with other family members or were someone else's total responsibility (Appendix B, Table 21a). Interestingly, family members perceived more diffusion of responsibility than did primary caregivers, particularly with regard to visits/companionship, telephone check-ups, transportation (in Group II only) and meal preparation (Appendix B, Table 21b). In addition, a sizeable proportion of primary caregivers (37% in Group I, 45% in Group II, 45% in Group III) perceived that they made the final decisions regarding the elderly relative, although family members saw more diffusion of responsibility here as well (58% in Group I, 57% in Group II, 41% in Group III: Appendix B, Table 12). Lastly, while more than half of caregivers had other family members participating in the project with them (Appendix B, Table 8), family participation rates in the project were limited. Family members attended only two or fewer counselling sessions (Appendix B, Table 16c), and not more than one educational workshop (Table 17). The majority did not attend any mutual support groups (74% in Group I, 58% in Group II, 55% in Group III: Appendix B, Table 18). These data lead one to conclude that primary caregivers were probably carrying most of the caregiving burden.

The findings regarding caregiving responsibilities and support tend to concur with Johnson's (1983) research where family members did not act as a shared-functioning unit in caring for elderly relatives, but rather one individual carried the majority of the responsibility and others stepped in if the primary caregiver was not available. Shanas (1979b) conceptualized this type of functioning as the "principle of substitution" rather than one of a "shared-functioning kinship system". This conceptualization seems to accurately capture the characteristics of the Caregiver Project's client group.

Data related to family member stressors (Appendix B, Table 10) indicated that in Group III there were more issues that were stressful for many family members than in the previous groups. In particular, conflict with the elderly relative (61% compared to 24% and 35%), time spent in care (57% compared to 32% and 42%), physical demands of care (54% compared to 21% and 35%) and limits on living one's own life (54% compared to 40% and 41%), were additional stressors for Group III, and were not particularly characteristic of Groups I and II. Although overall stress levels were consistent across all three groups and indicated moderate stress, Group III did show slightly more stress than the other groups (an average score of 2.8 compared to 3.3 and 3.2, where 1=overwhelming stress and 5=no stress). Similarly all groups rated caregiving as somewhat rewarding, but Group III felt slightly less rewarded than Groups I and II (an average score of 2.8 compared to 3.3 and 3.5, where 1=not rewarding and 5=very rewarding).

While these variations in family member stress levels are interesting, they were based on a small proportion of families. However, it is not surprising to find that more primary caregivers were stressed about specific issues and generally experienced a higher level of

stress than other family members (comparison of Appendix B, Tables 6 and 10), as they were bearing the bulk of the caregiving burden.

Data related to primary caregivers' and family members' knowledge about caregiving skills, the elderly relatives' condition and community resources were consistent across Groups I-III (Appendix B, Tables 5 and 9). Generally, knowledge levels were average to high in all areas according to caregivers, family members and social workers. Furthermore, needs for information about caregiving skills or relatives' conditions were infrequent, occurring in less than 38% of families (as identified in social work assessments, see Appendix B, Tables 7 and 14). These data lead one to question whether caregiver programs should focus on skill/knowledge development in counselling sessions or educational workshops, if knowledge levels were not low to begin with. Given the level of stress experienced by many caregivers, it may be worthwhile to channel program resources toward coping with stressful events rather than skill/knowledge development.

To summarize, primary caregiver and family data suggest:

- that the majority of caregivers served by the program were daughters in their early sixties who lived with their relative and did not work outside the home (with some chance variations by group).
- that the majority of caregivers were highly stressed in a number of areas (although there was some chance variation based on group).
- that primary caregivers bore most of the caregiving responsibility with minimal involvement of other family members, except perhaps when the caregiver was unavailable (substitution principle);
- that family members were less stressed than primary caregivers (again, with some chance variation by group), likely because they had fewer caregiving responsibilities; and
- that the focus on increasing caregiving skills/knowledge through counselling sessions and educational workshops may not be of primary importance for clients who seek assistance with caregiving issues.

4.6 Interpretations Re: Service Delivery/Participation Data

Intake and Assessment Services

The assessment interview was considered to be the first major point of service delivery for families participating in the project. Given that the project's intervention strategy was based on a short-term treatment model, assessments had to quickly and accurately focus on client needs so that plans of care could be devised and implemented immediately.

At assessment, clients in all three groups identified the following issues as major stressors/problems:

- worries about caregiving responsibilities (including concerns about time spent in caregiving, physical demands of caregiving and limitations on leading one's own life);
- worries about the future (both the caregivers' and the elderly relatives');
- conflict with elderly relatives (including having relatives accept advice); and
- absence of emotional support (including general feelings of high stress and no one to share worries with) (Table 6).

Social workers frequently identified the following client issues/needs based on their assessment interviews:

- relief from caregiving responsibilities (identified in all three groups);
- assistance with future planning (identified in Groups II and III only); and
- emotional support (identified in Groups II and III only) (Table 7 and 14).

Clients' plans of care in all three groups most frequently addressed the following issues/problem areas:

- relieving pressure from constant care of elderly relative;
- future planning;
- emotional support; and
- family conflict resolution (Table 19).

Taken together, intake/assessment data suggest that there was a fair degree of consistency between the nature of clients' identified problems, social workers' identification of intervention needs and the problem areas actually addressed during the intervention period (as indicated in client plans of care). However, clients did tend to feel stressed about conflicts with elderly relatives, yet these issues were not frequently addressed during the intervention (comparison of Appendix B, Tables 6 and 19). Resolution of family conflict was frequently addressed in plans of care, but was not often identified as an issue at intake (comparison of Tables 6 and 7 with 19).

Counselling Services

There was an increase in the number of counselling sessions offered (and attended) from the first group to the last two groups (Appendix B, Tables 16a and b). Feedback of results from process evaluation data following the first group suggested that clients in treatment Condition I (counselling only) were not receiving sufficient counselling service, particularly since this was the only form of intervention offered to these clients. An additional social worker joining the project after Group I increased the potential to offer more counselling services.

It is noteworthy, however, that there were few differences in the amount of counselling provided to clients in the various treatment conditions. It was initially expected that those in Condition III (where mutual support groups were offered) would spend less time in individual counselling sessions, since the group work was designed to decrease the need for counselling. Condition III was expected to be a cost-efficient means of service delivery. In fact, the need for counselling in this condition was essentially the same as in the other two conditions (Appendix B, Tables 16a and 16b), making this treatment alternative more costly. It is possible that the support groups offered in Condition III encouraged caregivers to address their problems, which in turn encouraged use of individual counselling time. It is also possible that counselling time could not be increased further (i.e. to more than four or five sessions) for Conditions I and II, given the brief time span for each treatment wave. Perhaps families could not handle and/or schedule frequent counselling sessions over a short time period. More time may have been required between sessions, but the constraints of the research did not permit extension of treatment phases to accommodate additional counselling needs.

Supplementary data gathered by the Project Director did, in fact, indicate that clients required additional intervention/contact than was offered in the "formal" treatment phase of the project: 68% of families completing the project called the program again at some point after their discharge interview. These calls resulted in face-to-face contact with 22% of the families who re-approached the program (approximately 3 additional sessions per family). They also resulted in telephone contact for advice or crisis intervention purposes with 62% of callers (approximately 2 additional conversations per family). Telephone contact for support or reassurance purposes occurred in 29% of call-back families (approximately 3 additional conversations per family). Twenty seven percent of callers requested referrals to additional services. Finally, additional contacts were also made with family members and collateral sources as a result of calls to the project following discharge.

These findings highlight the need for flexibility in delivering a short-term treatment service for caregivers. That is, a limited amount of service can be delivered in a short period of time, but periodically additional intervention will likely be necessary. Staffing resources and time to provide these additional services should be available and included in program budgets and schedules. In addition, research efforts must allow for variations in clients' service needs in order to capture more realistic and complete process and impact data.

Educational Workshops

Data related to educational workshops showed an increase in attendance over the three groups (average attendance = 10 in Group I, 15 in Group II, 18 in Group III: Appendix B, Table 17). While these workshops were primarily designed to provide information to caregivers in order to increase their knowledge and skill levels, the data indicate a second prominent focus. Workshops tended to focus on feelings about the caregiver role, emotional support, etc. (see Appendix B, Table 17), areas that one would expect to cover in mutual support groups. Perhaps this finding is not surprising in that social workers who were trained to deal with emotional content (and who were running the support groups as well) led the educational workshops. In addition, workshops consisted of fairly small groups of people rather than crowds in a mass educational session (as originally planned). This composition probably encouraged a supportive interactional format in the workshop. Finally, as noted earlier, caregivers did not feel they lacked knowledge (Appendix B, Tables 5 and 9) but felt fairly stressed about a number of issues (Appendix B, Table 6). Therefore, workshop participants themselves may have been directing the content of the meetings to meet their emotional/support needs. The factors highlighted above may account for the overlap between educational workshops and other treatment modalities.

Mutual Support Groups

Mutual support group data showed an increase in attendance from Group I to the later two groups (average attendance in Group I was 4, and 7 in each of Groups II and III: Appendix B, Table 18). Primary caregivers (not family members) were the participants in the support groups. For the most part, these groups operated as planned in that they focused on affective issues related to caregiving (e.g. feelings about relationships with elderly relatives, see Table 18).

It appears, then, that program resources were focused to a great extent on affective/emotionally supportive interventions. Perhaps future caregiver programs could offer mutual support groups and add extra sessions presenting educational material on an as-needed basis. Educational workshops would then be specifically focused on the knowledge gaps of particular groups of caregivers. An educational format offered as an adjunct to mutual support groups may be a more cost-efficient service delivery mechanism than providing workshops and support groups separately.

Referral Services

Data related to referral services offered by the Caregiver Project indicated that approximately half of participating families in each group were referred to additional services (Appendix B, Tables 20c and 20d). Given that in Groups I and II fewer than half the admitted families were involved with community resources, the data seem to indicate that the program was operating as originally planned by attempting to connect clients to community resources.

Family Members' Participation in Services

As noted in an earlier section, family members (other than the primary caregiver) from all three groups did not actively participate in any part of the project (Appendix B, Tables 16-18). Since the program was initially designed to serve family groups in order to encourage sharing of caregiving responsibilities, it is clear that the project did not operate as planned in this respect. Other family members who did participate in the project (and completed intake questionnaires) were largely children of elderly relatives, or spouses of primary caregivers. Involvement of third generation family members was minimal (22% of family members were grandchildren in Group I, 2% in Group II, 19% in Group III: Appendix B, Table 8). It may be unreasonable to expect that family members who have not been extensively involved in caring for their relative will suddenly agree to participate in this type of program with its intensive time commitments. Perhaps an important treatment goal for future caregiver programs should be for primary caregivers to recognize the need for assistance in the caregiving role and permit other family members to share the role.

One additional finding of note concerning service participation, is that elderly relatives did not generally participate in the program with their caregivers, although participation rates did increase in each year of project operations (0 relatives participated in Group I; 40% of relatives participated in Group II, 52% of elderly relatives participated in Group III: Appendix B, Table 16). Since elderly relatives were functioning at fairly high levels cognitively and physically, one might have expected them to be more involved in the program (in counselling sessions in particular). Anecdotal comments by the researcher conducting follow-up interviews with primary caregivers indicated that some caregivers did not want their relatives to know they were seeking assistance. This may be part of the reason why elderly relatives were largely uninvolved in the project.

Since the original design of the Caregiver Project did include involvement of elderly relatives, the program did not operate as planned in this area. It is important to ensure that "able" relatives participate with their caregivers, particularly since conflict between caregivers and elderly relatives is often an issue (see Appendix B, Table 6) and intervention plans are likely to involve the elderly person. Future caregiver services should encourage primary caregivers to actively involve their elderly relatives in portions of the intervention process that are relevant to their interactions and that relate to plans for the elderly person. Program staff need to encourage caregivers to include other family members and the elderly person in the caregiving process.

Staff Time Distribution

Original evaluation plans were designed to gather data on staff time spent in direct client contact and time spent in administrative types of activities (including research and evaluation). These data were to give a more detailed view of program costs, but they are not reported here because of errors in recording administrative activities. Tables 23a-c, therefore, present findings regarding time spent in direct service with clients and in research activity only.

Unexpectedly, counselling time with clients decreased across the three groups (an average of 8.1 hours per family in Group I, 7.8 hours per family in Group II, 6.7 hours per family in Group III: Appendix B, Tables 23a-c). It is possible that clinicians became more efficient at assessing and counselling caregivers (and their families), as they accumulated experience in this type of program.

The data regarding time spent in research and evaluation activity indicated that an average of 3.2 hours per week was invested during program start-up (Appendix B, Table 23a). One should note that service delivery to clients was limited during this time period and project staff were assisting in finalizing research instruments and were beginning to familiarize themselves with the evaluation tools. There was an increase in research time during the middle phase of program operations (7.2 hours per week, Table 23b), where most clients were seen and where difficulties with evaluation instruments were being identified and addressed. Finally, during the final year of program operations, research time decreased to an average of one hour per week (Table 23c). The decrease was likely due to the fact that staff became more efficient at completing research information and program activities were beginning to wind down.

Should future programs wish to monitor and evaluate their services, staff and time must be made available and included in program budgets and schedules.

Summary of Service Delivery/Participation Data

To summarize, service delivery/participation data suggest:

- client-identified problems and social workers' assessments of treatment needs fell into areas of: relief from caregiving responsibilities, planning for the future and emotional support. These areas were addressed in subsequent plans of care;
- conflict with elderly relatives was a client-identified problem that was not frequently addressed during interventions, while conflict with other family members was frequently addressed, but not initially assessed as a client problem area;
- it was difficult to provide sufficient counselling time to clients when constrained by research efforts;
- a short-term treatment model for caregivers needs to be flexible in the timing of its interventions and must provide staffing resources to accommodate a series of brief interventions over a longer period of time;
- treatment Condition III, which included counselling, education and mutual support groups, was not a particularly cost-efficient treatment modality, as originally expected;

- educational workshops should be combined with support groups and educational components should be derived from the needs of members of the support group. This may provide for a more cost-efficient service;
- intervention goals should focus on encouraging caregivers to permit other family members and the elderly relative to share in the caregiving process; and
- if caregiver services are to be monitored and evaluated, resources in terms of staff time must be made available for research efforts.

4.7 Interpretations Re: Additional Data Analyses

In an attempt to determine whether living arrangements and caregiver relationship to the elderly relative differentiated clients on a number of other process variables, two additional analyses (cross-tabulations) were generated. Data regarding caregiver needs in relation to proximity to elderly relatives (living arrangement) and characteristics of spouse versus non-spouse caregivers were produced and included information from all ten treatment waves combined.

Cross-tabulations of primary caregiver needs by proximity to elderly relatives (Table 24) produced a number of interesting results based upon whether the caregiver was actually living with the elderly relative:

- While all caregivers needed relief from caregiving responsibilities, a larger percentage of those living with their relative required relief compared to those who lived away from the family member (88% versus 56%, Table 24). This concurs with Deimling, Bass, Townsend and Noelker (1989) who found that shared living arrangements restrict caregivers' activities (and increase strain) more than non-shared living arrangements.
- The need for caregivers to resolve conflict with elderly relatives and understand their relatives' own choices and needs was more prominent in the group which did not live with the family member (56% compared to 37% re resolving conflict, 30% compared to 9% re understanding choices and needs, Appendix B, Table 24). These findings concur with those of Deimling et al (1989) and Gottleib (1989). They contend that there are more likely to be long standing negative relationships between caregivers and relatives who do not elect to live together compared to those who do live together. Similar relationships may have accounted for the differences in the need to resolve conflicts and

increase understanding of relatives' choices in the current study.

Cross-tabulations comparing spouse and non-spouse stressors and needs (Appendix B, Table 25) showed a few minor differences. Deimling et al's research (1989) also indicated few differences on a variety of variables based on relationship to the elderly person. Interpersonal conflicts were slightly higher in non-spouse as opposed to spousal relationships in this study (63% compared to 53%: Appendix B, Table 25). Similarly social workers' assessments of caregiver/relative relationships reflected slightly more conflict with non-spouse as opposed to spouse caregivers (48% compared to 34%). These findings were not surprising in that non-spouse caregivers were usually the children of elderly relatives and long standing parent-child conflicts may still have been evident. New conflicts may have arisen as children were required to take on caregiving roles.

To summarize, there were some differences in caregiver stressors and needs based upon proximity and relationship to the elderly relative. Awareness of these potential differences may assist in identifying specific service needs more rapidly.

5.0 OUTCOME EVALUATION FINDINGS

5.1 Introduction

To briefly reiterate earlier portions of this report, outcome data were obtained from the following measurement sources throughout the three years of service delivery:

- Primary Caregiver Intake, and Follow-up I and II questionnaires/interviews;
- "other family members" Intake and Follow-up I and II questionnaires/interviews;
- the Family Assessment Measure (FAM);
- clinical recording systems used at intake, discharge and Follow-up III time periods; and
- general program information systems developed for this project.

The impact of the service was examined along several dimensions:

Family functioning outcomes in specific areas of cooperation, conflict, involvement in care, caregiver stress levels, competence/comfort with the caregiving role and situational changes affecting the ability to provide care were assessed. Separate one-way analyses of variance with treatment condition or group were used in the analysis of the first five variables. Difference scores across measurement points served as the dependent variables in these analyses. Situational changes affecting the ability to provide care were examined using frequencies across the complete sample.

Additional family functioning changes were examined in the areas of cooperation, conflict and stress levels with relationship to the elderly person (spouse, non-spouse) as the comparative factor. One-way ANOVAs with difference scores across measurement points were used in these analyses.

Program impacts related to changes in knowledge or skill levels focused specifically on understanding the elderly relative's condition, awareness and use of community resources and gaining practical caregiving skills. One-way analyses of variance, Chi^2's and frequencies with condition and groups as factors were used in these analyses. As above, ANOVAs employed difference scores across measurement points as dependent measures.

Outcomes concerning changes in quality of care were examined through one-way ANOVAs with treatment condition and group as factors and difference scores as dependent measures.

Changes in the status of elderly relatives and achievement of treatment goals were assessed in terms of frequencies for each treatment condition.

Finally, **client satisfaction with various treatment components and with the service as a whole** was analyzed via ANOVAs and frequencies comparing the three treatment conditions.

Significant ANOVA results and frequency data are presented in Appendix C, Tables 1-12. Subsequent sections of this report highlight relevant tables/data as they relate to interpretations of the findings.

5.2 Variations in Availability of Outcome Data

Although 125 families actually completed the program (49 from Condition I, 39 from Condition II and 37 from Condition III or 31 from Group I, 41 from Group II and 53 from Group III), the availability of data for each of the individual analyses varied.

First, data from ten families were eliminated from any analyses involving measures from Follow-up I, II or III time periods. It was necessary to eliminate these data because the first follow-up interview occurred too long after clients' discharge from the program (more than 20 weeks post discharge), making it difficult to determine whether results at any of the follow-up periods were due to program effects or to other unknown factors. While data from these ten families were not included in analyses involving follow-up measures, they were included in analyses using intake and discharge measures.

A second reason for variations in the amount of data for individual outcome analyses stems from the fact that clients were available to provide information at some of the measurement points but not at others, while some clients provided data at all points in time. If outcome analyses were to include only those families who had provided information at intake, discharge and Follow-up I-III points, too much valuable data would have been lost. Therefore, whenever data were available they were included in the analyses, causing variations in the number of cases analyzed.

A third and final reason for differences in the number of cases included in analyses resulted from missing data within each measure. Respondents did not always provide answers to

each question asked at each measurement point. Cases with missing data on a particular outcome variable were eliminated from the analysis in question.

As noted in the section on process evaluation results, only limited data from family members other than the primary caregiver were available and these data were not highly representative of the majority of families. Process findings also indicated that family members participated in services offered by the Caregiver Project in only about 50% of the cases (Appendix B, Table 16). For these reasons the impact of the program on or from the family member perspective was not assessed. In other words, outcome analyses were conducted only for primary caregivers. FAM data for primary caregivers was also eliminated from outcome analyses because of the large number of invalidated questionnaires (see Appendix B, Table 11).

5.3 Treatment Condition Effects and Interpretations

In general, few significant findings emerged as a result of the comparative analyses of the three treatment conditions employed in the Caregiver Project. However, the reader should be aware that these results do not mean that services offered had no impact, but rather, that there was no **differential** impact based on the treatment modality employed. Since the design of this study did not include a "no treatment" control group, but did include systematic variations in treatment groups, conclusions can only be drawn about the differences between the interventions offered and not about the overall effectiveness of the program.

The fact that there were few significant differential outcomes on variables related to family/caregiver functioning, knowledge/skill levels, quality of care, percentage of treatment goals achieved (see Appendix C, Table 8a) suggests that caregiver programs should opt for the least costly intervention technique. In the case of the current project, the "counselling only" (Condition I) intervention, was the least costly treatment modality in terms of staff time. The availability of additional treatment techniques in Conditions II and III did not decrease the need for counselling sessions as initially expected (see comments on page 26 and Table 16a, Appendix B), making these two treatment alternatives more costly with equivalent impacts to Condition I. Furthermore, a sizeable proportion of clients in all three treatment conditions seemed to like the counselling/talking components of the service (55% in Condition I, 83% in Condition II, 58% in Condition III (Table 11, Appendix C).

However, some additional data related to client satisfaction with various treatment components may dampen the zeal with which one would choose the least costly intervention, i.e. counselling only. As indicated in Appendix C, Table 11, 23% of clients in Condition I found nothing useful about the service compared to 0% in Conditions II and III. In addition, more clients in Conditions II and III would recommend the Caregiver Program to others when compared to Condition I participants (87% for Condition II, 93% for Condition III compared to 69% for Condition I, Table 12a, Appendix C). Similarly, more Condition I clients would not recommend the program when compared to the other two groups of caregivers (14% for Condition I, 7% for Condition II, 0% for Condition III, Table 12a).

Taken together, the findings concerning the cost-effectiveness of various treatment modalities and the greater degree of dissatisfaction in Condition I (counselling only), suggest that caregiver services should primarily offer counselling, with some additional group sessions on an as needed basis. As indicated in the process evaluation section, group work would be most efficiently and effectively conducted as a combination of mutual support and educational programming, tailored to the specific needs of the participants.

The fact that differential treatment effects did not emerge with respect to a number of variables is not particularly surprising. Process data indicated that many caregivers were not experiencing a great deal of conflict with other family members, lack of cooperation, feelings of incompetence and knowledge deficits when they entered the program. The quality of care provided to elderly relatives was also moderately good prior to involvement in the Caregiver Project. Since clients did not experience difficulties in these areas to begin with, one should not expect change on these factors as a result of a particular type of treatment.

It is also not surprising that the intervention models had no differential impact on family involvement in caregiving. Since family participation rates were low, one would not expect changes in caregiving involvement due to program interventions. However, the absence of outcomes in this area, once again highlights the need for future services to teach caregivers how to include other family members in the care process. Direct involvement of the family in treatment may not be required.

Given that pre-intervention stress levels were high, differential treatment effects on stress levels were expected. Specifically, it was expected that Condition III, which provided maximal opportunities for emotional support, would produce the most positive outcomes in terms of stress reduction. There was, however, no differential treatment effect when compared by treatment condition. The findings and interpretations of a study by Toseland, Rossiter and Labrecque (1989), may offer some useful explanations for the results of the current investigation. They examined the effectiveness of three group intervention strategies supporting caregivers of elderly persons. Their results indicated significant changes in personal problems and coping related to caregiving, but there were no significant effects on measures of psychological status and caregiving burden (i.e. stress). These authors concluded that in short-term intervention models, social support and coping skills may be achieved but more deeply rooted psychological difficulties related to stress levels may not be altered. Furthermore, the causes of caregiver stress do not decrease following intervention. As the ageing process continues, elderly relatives require more care, creating more stress. Perhaps, then, stress reduction was too ambitious an outcome for some types of clients in the Caregiver Project. Other types of treatment effects related to feelings of support, coping with day-to-day caregiving situations, etc., may have provided additional useful data for the project.

An additional treatment outcome of note relates to the mutual support group component of Condition III. It was initially expected that groups would continue to function on their own, beyond the professionally-led sessions offered by the Caregiver Project. This did not occur. Perhaps it was unrealistic to expect busy caregivers to assume the responsibility for organizing further groups. In addition, professionally-led groups may be perceived as a more credible means of acquiring assistance than participant-led groups, accounting for

group termination following the formal intervention period. Lastly, caregivers may not have required additional sessions beyond those offered by the Caregiver Project.

One final outcome of interest concerns a variable scored from the project staff perspective. That is, social work staff perceived an increase in treatment Condition III in clients' awareness of community resources from intake to discharge timeframes ($F=3.24, df=2,110, p<.04$, Appendix C, Tables 5a and 5b). Interestingly, caregivers did not perceive these changes, as indicated by non-significant findings on the same variables scored from the client perspective. Since staff were not blind with respect to client treatment condition, it is possible that their knowledge biased their scores on this particular variable.

To summarize, the findings and interpretations related to treatment condition effects suggest:

- that since differential treatment impacts did not emerge, future caregiver services should employ counselling interventions with additional group work (supportive and educational) on an as-needed basis;
- that outcome measures related to changes in family conflict, cooperation, feelings of competence, knowledge/skill levels were of little relevance given the fairly intact status of the Caregiver Project's client group in these areas;
- that absence of changes in family involvement in care could be explained by low participation rates of family members in project services;
- that expected outcomes related to reduction in psychological stress levels may be too ambitious for some clients participating in a short-term intervention. Feelings of support and ability to cope may be useful additional indicators of program impact.
- that one should not necessarily expect mutual support groups to continue beyond professionally-led sessions because clients may not need the additional groups, they may not have the time to organize sessions and/or may perceive that social work leadership lends more credibility to the meetings.

5.4 Group Effects and Interpretations

While differential treatment effects did not emerge as a result of specific interventions offered by the Caregiver Project, some significant outcomes corresponding to time of entry into the program (i.e., during start-up, the middle or final year of operation) did occur. For example, there was a reduction in stress due to family conflict ($F=3.94, df=2,81, p<.02$) from Follow-up I to Follow-up II measurement points (see Appendix C, Tables 1a and 1b). Post-hoc analysis indicated that clients in Group I experienced more stress reduction than clients

in the other two groups. There was also a significant group effect related to stress reduction on a combination of specific stressors ($F=3.73, df=2,61, p<.03$) from Intake to Follow-up II time periods (see Appendix C, Tables 3a and 3b). Post-hoc analysis showed that Group I clients did significantly better than Group III clients. Because caregiver stress was such a salient issue in the process data, results of non-significant outcome analyses related to reduction in general stress levels are provided in Appendix C, Tables 2a and 2b.

Significant differences were also obtained in relation to family involvement in care from Intake to Follow-up II ($F=5.20, df=2,105, p<.01$: Appendix C, Table 4a) and from Follow-up I to Follow-up II ($F=3.88$, $df=2,104$, $p<.02$). Here, post-hoc results indicated that Group I caregivers experienced more diffusion of responsibility of caregiving tasks than did Group II and Group III caregivers.

It seems, therefore, that Group I may have been more responsive to intervention, as indicated by a reduction in stress relative to Group III and increased diffusion of responsibility relative to Groups II and III.

5.5 Other Effects and Interpretations

Further outcome data related to use of community resources were available from only a small number of clients across all conditions and groups. Those that did provide data indicated that they learned about community agency, day-care and home care resources from the Caregiver Program. They also indicated that impediments to use of existing resources were: ineligibility of their relative for service, resistance on the part of elderly relatives and failure of the resources to meet service needs of elderly relatives. Although a minority of project participants supplied this information, it suggests that families should be prepared for the fact that programs may not work out for their elderly relative and/or that service or space may not be available to them.

Other outcome findings of interest concern the status of elderly relatives following their family's discharge from the Caregiver Project. Basically, at discharge relatives in all treatment conditions remained in the same home location as at intake (85% for Condition I, 83% for Condition II, 94% Condition III, Appendix C, Table 6a). Similarly, at the Follow-up III point (approximately six months post discharge) most elderly relatives were still in the same home (71% for Condition I, 70% for Condition II, 76% for Condition III, Appendix C, Table 6b), although more acute care hospitalization and institutionalization did tend to occur at this time. However, one cannot conclude that the Caregiver Program served to keep elderly relatives out of institutions, since most caregivers indicated that institutionalization was never really an issue at the outset. Furthermore, process data suggested that elderly persons were functioning at fairly high levels and would therefore not be likely to require institutionalization within six months of discharge from the Caregiver Project. Rate of institutionalization was not a particularly relevant outcome measure for the client group participating in the caregiver project.

While the status of the elderly relative seemed to remain fairly stable post discharge, a fair proportion of caregivers (49% at discharge, 68% at Follow-up III) felt there were situations affecting their ability to provide care (see Appendix C, Table 7a and 7b). These data

suggest that the caregiver environment (and its related stresses) changes very rapidly. This information, coupled with the additional Project data showing substantial client call-back rates, reinforces the need for flexibility and availability of staff to provide periodic short-term interventions to the same families on an as-needed basis.

To summarize, the findings and interpretations related to other outcome effects suggest:

- that the relevance and lack of availability of particular community resources should be discussed with clients during the referral process;
- that outcome measures related to institutionalization were of little relevance given the fairly intact status of elderly relatives; and
- that situational changes affecting caregivers' ability to provide care can emerge fairly soon after an intervention period. Therefore program resources need to be available to provide repeated short-term assistance to clients.

6.0 OVERVIEW OF FINDINGS AND INTERPRETATIONS

The preceding sections of this report have presented a large number of findings and interpretations. In order to draw together the results of the evaluation of the Caregiver Project, the key findings and conclusions of the study are reiterated below.

6.1 Client Characteristics

The characteristics of the client group served by the project were identified through the process evaluation portion of the study.

The majority of caregivers served by the program were primary caregivers who were daughters in their early sixties living with their elderly relatives and not employed outside the home. These caregivers were highly stressed in a number of areas and bore most of the caregiving responsibility with minimal involvement of other family members. They were caring for elderly relatives who were operating at fairly high levels cognitively and functionally, and had only recently entered the social service system regarding caregiver issues. The fact that these individuals were caring for fairly "intact" relatives, but were highly stressed early on in the caregiving process suggested that these clients represented an important sub-population of caregivers not previously identified as being in need of services. In general, areas in which clients needed assistance were: relief from caregiving responsibilities, planning for the future, emotional support, and to some extent, resolving conflicts with elderly relatives. Interventions related to caregiver skill development and increasing knowledge were not of primary importance in this caregiver sample.

Conclusions regarding a variety of aspects of the service delivery model and process (from referral and intake to discharge and further referral) were generated from both process and outcome evaluation portions of the study.

6.2 Referrals to the Service

Although referrals (largely self-referrals) to the program were appropriate, it was a constant struggle to keep up referral rates. At least one year of program operations was required to develop a consistent rate of referral. Public advertising and increasing awareness of the program within Baycrest itself augmented referrals to some extent. However, the fact that other assessment, counselling and referral services were available within Baycrest likely hindered referrals. In addition, other caregiver-specific programs became more widely available in the same catchment area also contributing to referral difficulties. Therefore, coordination of caregiver services within sponsoring institutions and at the community and government levels will be essential as additional programs continue to emerge.

Since some of the Caregiver Project's services can be and were available in other programs for the elderly and since referrals were difficult to generate, it is suggested that such services should not operate as "stand-alone" programs but should be added to existing services.

6.3 Family Involvement in Service

Clinicians were able to quickly assess client needs which corresponded to client-identified stressors and developed plans of care which were consistent with specified needs. Rapid and accurate assessments and intervention strategies are essential to a short-term treatment model. However, an important intervention goal in future services, which was not often included in plans of care in this project, would be to encourage caregivers to include other family members and elderly relatives to share in the caregiving process. Lack of family participation in the Caregiver Project, few instances of change in family involvement in care as a result of the services offered, and the degree to which primary caregivers bore most of the caregiving responsibility, all support the conclusion that future interventions should focus on assisting caregivers in sharing the caregiving role.

6.4 Counselling, Mutual Support Group and Educational Services

The fact that differential treatment impacts did not emerge from this study suggests that future caregiver services should employ counselling interventions (the least costly treatment modality) with additional group work (supportive and educational) on an as-needed basis.

The counselling aspect of service delivery tended to be constrained by the research effort's time limits. Many clients needed additional service which could not be provided within the time frame of a single treatment wave. Situational changes affecting caregivers' ability to provide care tended to emerge fairly soon after the intervention period. Therefore a short-term treatment model for caregivers needs to be flexible in the timing of its counselling interventions and must provide staffing resources to accommodate a series of brief interventions over a longer period of time.

If clients are to receive counselling services as well as group interventions in the form of mutual support groups and educational input, all interventions should be spread over a longer time period. More realistic time demands may decrease service dropout rates.

Since educational workshops and mutual support groups tended to overlap in content and format, and since educational input was not a critical issue for caregivers, future interventions should combine these types of groups in order to provide more cost-efficient service.

Although the support group component of the service was considered to be quite useful by client participants, contact among its members did not continue beyond the professionally-led sessions. It may be unreasonable to expect continuation of these groups because clients may not require additional sessions, they may not have the time to organize more groups and/or may prefer professionally-led sessions.

6.5 Referrals to Other Services

Since a small group of clients did experience impediments in obtaining community resources which had been suggested by project staff, the relevance and lack of availability of particular services should be discussed with clients during the discharge and referral process.

6.6 Indicators of Program Impact

Finally, several conclusions related to indicators of program impact emerged as a result of findings from both process and outcome evaluations.

Given the relatively high level of functioning of caregivers, families and elderly relatives, outcome measures related to changes in family conflict, cooperation, feelings of competence, knowledge/skill levels and elderly relatives' status re institutionalization were of low relevance. Furthermore, expected outcomes related to reduction in psychological stress levels may have been too ambitious for some clients participating in a short-term treatment model. Feelings of support and ability to cope may be additional useful indicators of impact in future programs.

Problems with the research methodology for the Caregiver Project have been alluded to throughout this report and have been addressed to some degree above. A more comprehensive discussion of the research effort and suggestions for future evaluations are offered as the final section of the report.

7.0 SUGGESTIONS FOR FUTURE RESEARCH

As indicated throughout this report, the research effort tended to put unrealistic constraints on the service delivery process, the clients and project staff. To a certain extent the interventions offered were tailored to accommodate the evaluation requirements, rather than vice versa. The net result was that the evaluation was not assessing interventions as they would be delivered in the "real world" but rather a modified version of caregiver services.

One area of difficulty was the use of random assignment to one of three treatment conditions. While the research assumption underlying this type of random assignment procedure is that there is no a priori reason to believe that one form of treatment is better

suited to clients than another, the same assumption may not hold when clinicians actually offer services to clients. Informal comments from project staff with regard to a number of clients, indicated that had random assignment not been in place, they would have offered a different type of service than the one actually assigned. Furthermore, process evaluation data suggested that a number of clients screened themselves out of the program after their intake/assessment interview likely because they would not be receiving the service they expected and/or wanted. The project therefore lost potential participants, whom it could ill afford to lose.

Rather than using random assignment procedures in future research efforts, service participants could be offered the intervention to which they were best suited. Clients actually included in the research would be in treatment groups that were constructed to be equivalent on a number of key caregiver and elderly relative characteristics. This procedure would be less disruptive to the intake process.

A second problem area with the current research methodology concerned the criteria for considering clients as project dropouts. A client/family had to participate in at least half of the services offered in the condition to which they were assigned in order to be part of the research effort. Obviously then, Condition I clients could participate in very little service (two counselling sessions) and still be included in the research, while clients in Condition III could have made use of a number of services, but be considered as dropouts. By eliminating clients who did use services to some extent, valuable outcome data may have been lost.

Two possible solutions to the above problem are suggested. First, clients who use a limited amount of service could be compared as a group to those who take full advantage of treatments offered. Second, the number of sessions/groups attended could be used as a statistical covariate in data analyses in order to determine if the actual amount of treatment had an effect on project outcomes. In this way, valuable outcome data would still be included in the evaluation.

Another area of difficulty highlighted throughout this report was the use of time-limited treatment waves. Project participants were expected to attend a number of sessions in a very short time period, which was likely an unrealistic expectation. In addition, clients were often not ready to be discharged when the prescribed time period for a particular wave was over. Indeed many called back for additional services, but information related to continued service was not formally included in the data collection procedures. These problems arose because the research design was mounted without a clear sense of the natural flow of the treatment process. Therefore, it is suggested that before mounting an outcome evaluation of a pilot project, the service should be permitted to operate for a year. By then project staff would have a better idea of how the intervention process functioned and could give researchers guidance in the development of realistic but minimally intrusive evaluation designs and procedures.

The current report also suggested that a number of the outcome measures employed in the evaluation of the Caregiver Project were of low relevance. This difficulty was likely due to the fact that the outcome evaluation was designed before the actual characteristics of participants were known. For example, many clients did not require practical caregiving

skills, but increased skill level was an expected outcome of service. Once again it is suggested that a pilot project should operate for a year to get a clearer sense of client needs, the required interventions and associated impacts. At that point outcome evaluation plans can be mounted using more relevant indicators of program success and failure. Furthermore, as more evaluations of services for the elderly and their families are conducted, more standardized, reliable and valid measures of service outcomes will be available to researchers and program operators.

Finally, if Baycrest should continue to operate some form of caregiver service without the resources for a full-scale evaluation, it is suggested that the program be monitored by collecting some process data on an on-going basis. In particular, information related to client characteristics (caregiver and elderly relative), client needs from both social work and client perspectives, content of plans of care, amount of service delivered, participation and dropout rates, and client satisfaction (collected anonymously), should be gathered. In this way, periodic analysis of the information can provide a basis for refinement of services over time. However, service operators must ensure that staff resources are made available to collect these types of data on an on-going basis.

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APPENDIX A

SPECIFIC RESEARCH QUESTIONS, ASSOCIATED MEASURES AND DATA COLLECTION POINTS

PROCESS QUESTIONS (and where they are addressed in report)	OUTCOME QUESTIONS (and where they are addressed in report)	MEASURES & TIME FRAMES PROGRAM RECORDING SYSTEMS (ongoing)	BAYCREST INTERVIEWS (assessment/intake, discharge, follow-up III)	PRIMARY CARE-GIVER QUESTIONNAIRES (intake, follow-up I & II)	OTHER FAMILY MEMBER QUESTIONNAIRE (intake, follow-up I)	FAMILY ASSESSMENT MEASURE (intake, follow-up I)
DEMOGRAPHICS						
• What are the demographic characteristics of families (age, sex, work status), served by the program (pp 21-24, 39)			At assessment/intake only			
REFERRALS						
• Number of referrals		●				
• Sources of referrals		●				
• Are any families screened out? If so why? (pp 17-20, 40)		●				
ASSESSMENT						
• Number of assessment interviews completed? (Table 15, Appendix B)		●				
FAMILY DYNAMICS						
• What is the nature of the relationship (at assessment) between the elderly person and the family? How often and over what issues does this relationship produce stress? (pp 22-24)	• Does the project have a positive impact on family functioning? Is there a reduction of anxiety and conflict among family members? (pp 34-38, 39)			●	●	●

PROCESS QUESTIONS (and where they are addressed in report)	OUTCOME QUESTIONS (and where they are addressed in report)	MEASURES & TIME FRAMES				
		PROGRAM RECORDING SYSTEMS (ongoing)	BAYCREST INTERVIEWS (assessment/intake, discharge, follow-up III	PRIMARY CAREGIVER QUESTIONNAIRES (intake, follow-up I & II)	OTHER FAMILY MEMBER QUESTIONNAIRE (intake, follow-up I)	FAMILY ASSESSMENT MEASURE (intake, follow-up I)
FAMILY DYNAMICS <CONT>						
• What is the family composition (living with elderly relative, not living with relative? How are third and fourth generation family members involved in care? (pp 21, 22-23, 28-29)	• Are family members more involved in care? (pp 35, 36, 37, 38)			●	●	
• How are family decisions made about care of the elderly relative? (p 22)				At intake only	At intake only	
• What are the strengths of the family? (Table 13, Appendix B)			At assessment/intake only			
• What are the family's needs? (Table 14, Appendix B)			At assessment/intake only			
	• Were there changes in the family's situation which affected their ability to provide care? (pp 38, 39)		At discharge and follow-up III only	At follow-up II only		

PROCESS QUESTIONS (and where they are addressed in report)	OUTCOME QUESTIONS (and where they are addressed in report)	MEASURES & TIME FRAMES			
		PROGRAM RECORDING SYSTEMS (ongoing)	BAYCREST INTERVIEWS (assessment/intake, discharge, follow-up III)	PRIMARY CAREGIVER QUESTIONNAIRES (intake, follow-up I & II)	OTHER FAMILY MEMBER QUESTIONNAIRE (intake, follow-up I)	FAMILY ASSESSMENT MEASURE (intake, follow-up I)
KNOWLEDGE						
• What level of knowledge/understanding of the elderly relative's condition is exhibited by the caregivers? (pp 23, 24)	• What knowledge increases have there been about the elderly relative's condition? (pp 34, 35, 36)		At assessment/intake and discharge only	●	●	
• What level of knowledge/understanding does the family have about caregiving skills? (pp 23, 24)	• Has the family learned practical care-giving skills? (pp 34, 35, 36)		At assessment/intake and discharge only	At follow-up I only	At follow-up I only	
• What level of awareness is there among family members of community resources? What resources are currently used? What impediments are there to use of existing resources? (pp 18-19, 28)	• Was there increased use/knowledge of community resources? Were there impediments to use of existing resources? (p 38)		At assessment/intake and discharge only	At follow-up I and II only		
PRIMARY CAREGIVER						
• What are the specific needs of primary caregivers? (p 24-25)		At assessment/intake only				
• What specific stressors are faced by caregivers in terms of social isolation privacy, need for relief, ability to participate in jobs/ recreation/ vacations? (pp 22, 23, 24-25, 29-30)	• Has there been a decrease in primary caregiver stress levels? (pp 35, 36, 37)		●			

PROCESS QUESTIONS (and where they are addressed in report)	OUTCOME QUESTIONS (and where they are addressed in report)	MEASURES & TIME FRAMES: PROGRAM RECORDING SYSTEMS (ongoing)	BAYCREST INTERVIEWS (assessment/intake, discharge, follow-up III)	PRIMARY CAREGIVER QUESTIONNAIRES (intake, follow-up I & II)	OTHER FAMILY MEMBER QUESTIONNAIRE (intake, follow-up I)	FAMILY ASSESSMENT MEASURE (intake, follow-up I)
PRIMARY CAREGIVER <CONT>						
• What are the primary caregivers feelings of comfort/competence with the caregiver role (pp 35, 36)	• Does the primary caregiver feel more competent/comfortable with the caregiving role? (pp 35, 36)			•		
ELDERLY PERSON						
• What type and level of impairment and/or disability are manifested by the elderly person? (pp 20-21)			At intake/assessment only			
• What are the perceived needs for institutional care at present and in the future? (p 21)	• What proportion of elderly persons remained at time, did or were institutionalized? (p 38)		•	•		
OTHER ASSESSMENT QUESTION						
• What is the quality of care provided? (Table 22, Appendix B)	• Has the quality of care improved? (pp 34, 35)		At assessment/intake and discharge only			
COUNSELLING						
• Number of sessions held with each family? (pp 26-30)		•				
• Which family members participated? (Table 16, Appendix B)		•				

PROCESS QUESTIONS (and where they are addressed in report)	OUTCOME QUESTIONS (and where they are addressed in report)	MEASURES & TIME FRAMES: PROGRAM RECORDING SYSTEMS (ongoing)	BAYCREST INTERVIEWS (assessment/intake, discharge, follow-up III)	PRIMARY CARE-GIVER QUESTIONNAIRES (intake, follow-up I & II)	OTHER FAMILY MEMBER QUESTIONNAIRE (intake, follow-up I)	FAMILY ASSESSMENT MEASURE (intake, follow-up I)
PLAN OF CARE						
• Was a plan of care developed? (Table 19, Appendix B)		●				
• Types of service goals addressed in plan of care? (Table 19, Appendix B, pp 25, 30)	• Is there evidence that service goals for individual family groups have been achieved? (pp 34, Tables 8 & 9, Appendix C)	●				
• Do service objectives relate to identified needs? (pp 24-25, 28-29)		●	At assessment/intake only			
SUPPORT GROUPS						
• Number of support groups held? (Table 18, Appendix B)		●				
• Content of meetings? (p 27)		●				
• Number of attending meetings? (p 27)		●				
• Who attends meetings? (p 27)		●				

PROCESS QUESTIONS (and where they are addressed in report)	OUTCOME QUESTIONS (and where they are addressed in report)	MEASURES & TIME FRAMES				
		PROGRAM RECORDING SYSTEMS (ongoing)	BAYCREST INTERVIEWS (assessment/intake, discharge, follow-up III)	PRIMARY CAREGIVER QUESTIONNAIRES (intake, follow-up I & II)	OTHER FAMILY MEMBER QUESTIONNAIRE (intake, follow-up I)	FAMILY ASSESSMENT MEASURE (intake, follow-up I)
SUPPORT GROUPS <CONT>	• Do Mutual Support Groups develop into self-help groups? What is the frequency of reciprocal aid among group members following discharge from the project? (pp 36, 37)			At follow-up II only		
EDUCATIONAL WORKSHOPS						
• Outside resources used? (Table 17, Appendix B)		•				
• Number of workshops held? (Table 17, Appendix B)		•				
• Content of workshops? (p 27)		•				
• Who attends workshops? (Table 17, Appendix B)		•				
OTHER TREATMENT QUESTIONS						
• Number of families admitted to each of the three treatment conditions? (Table 1, Appendix B)		•				

PROCESS QUESTIONS (and where they are addressed in report)	OUTCOME QUESTIONS (and where they are addressed in report)	MEASURES & TIME FRAMES: PROGRAM RECORDING SYSTEMS (ongoing)	BAYCREST INTERVIEWS (assessment/intake, discharge, follow-up III)	PRIMARY CARE-GIVER QUESTIONNAIRES (intake, follow-up I & II)	OTHER FAMILY MEMBER QUESTIONNAIRE (intake, follow-up I)	FAMILY ASSESSMENT MEASURE (intake, follow-up I)
DISCHARGE						
• Number of families completing the program? (p 33)		●				
• Number of referrals made to outside agencies? Sources referred to? (Table 20 c & d)		●				
TRANSFERABILITY						
• How is staff time distributed across various activities of the project (direct service/administration)? (pp 29-30)		●				
• What problems occurred in the implementation of the project?	• What is the level of client satisfaction with the project overall, as well as with specific components? (pp 34-35)	●		At follow-up I only	At follow-up I only	
	• Do particular project components seem to be more effective than others? (p 34)	●	●	●	●	●
• Are project activities consistent with project objectives?		●				

PROCESS QUESTIONS (and where they are addressed in report)	OUTCOME QUESTIONS (and where they are addressed in report)	MEASURES & TIME FRAMES				
		PROGRAM RECORDING SYSTEMS (ongoing)	BAYCREST INTERVIEWS (assessment/intake, discharge, follow-up III)	PRIMARY CARE-GIVER QUESTIONNAIRES (intake, follow-up I & II)	OTHER FAMILY MEMBER QUESTIONNAIRE (intake, follow-up I)	FAMILY ASSESSMENT MEASURE (intake, follow-up I)
TRANSFERABILITY <CONT>						
• Attrition rates from project components? (pp 19, 20)		●				
• What are the costs in staff (time) associated with implementing individual components of service? (p 29)	• Is there any evidence of the cost-effectiveness of various components of the service model? (pp 34, 35)	●				

APPENDIX B

PROCESS ANALYSIS RESULTS

TABLE 1 - SAMPLE DISPOSITION

	Group I	Group II	Group III
No. Families Referred	66	96	128
No. Families Admitted	42 (64% of referrals)	58 (60% of referrals)	76 (55% of referrals)
No. Families:			
- Condition I	14	20	17
- Condition II	5	18	32
- Condition III	23	20	27
No. Screened Out	24 (36% of referrals)	38 (40% of referrals)	52 (41% of referrals)
Reasons:			
- caregiver did not live in the area	2	7	7
- service duplication	6	1	3
- no identified caregiver	0	0	3
- caregiver felt service inappropriate	11	26	34
- social worker felt service inappropriate	4	3	1
- health change (in elderly or caregiver)/death	3	0	2
- placement pursued	3	6	3
- no time to participate	2	3	1
- other	2	1	1
No. Dropouts*	11 (26% of admitted families)	17 (29% of admitted families)	23 (30% of admitted families)
Reasons:			
- caregiver felt service inappropriate	5	10	7
- crisis arose	2	0	0
- no time to participate	4	7	13
- health charge (in elderly or caregiver)	0	0	1
- elderly relative died	0	0	1
- client would not participate in research	0	0	1
No. Completing Program	31 (74% of admissions)	41 (71% of admissions)	53 (70% of admissions)

The majority of dropouts are from Condition III.

TABLE 2 - REFERRAL SOURCES

Source	Group I		Group II		Group III	
	All Referrals (N = 66)	Admitted Families (N = 42)	All Referrals (N = 96)	Admitted Families (N = 58)	All Referrals (N = 128)	Admitted Families (N = 76)
Family	65%	76%	71%	80%	62%	71%
Community Acute Hospital	3%	2%	1%	2%	2%	3%
Community Agency	4%	2%	0	0	2%	3%
Paramedical	3%	0	7%	3%	4%	5%
J.F. & C.S.*	2%	0	1%	0	1%	0
Physician	2%	0	1%	0	2%	3%
Baycrest Daycare	2%	2%	1%	2%	0	0
Baycrest Hospital	9%	5%	5%	4%	14%	11%
Baycrest Intake	3%	5%	9%	4%	3%	3%
Other	7%	8%	5%	4%	10%	2%

*Jewish Family & Child Service.

TABLE 3 - WHERE REFERRAL SOURCES HEARD ABOUT PROGRAM

	Group I (N = 42)	Group II (N = 58)	Group III (N = 128)
Media	19%	38%	23%
Friends/Relatives	10%	9%	9%
Baycrest Professionals:			
- nurse	2%	0	1%
- social Worker	19%	26%	22%
- physician	2%	2%	6%
- other	7%	7%	24%
Community Professionals:			
- social Worker	19%	3%	5%
- physician	2%	2%	1%
- nurse	5%	2%	2%
- other	5%	9%	7%
- missing data	10%	3%	1%

TABLE 4 - ELDERLY CHARACTERISTICS

	Group I (N = 48)	Group II (N = 63)	Group III (N = 76)
Average Age	81 yrs.	78 yrs.	80 yrs.
Males	50%	37%	33%
Females	59%	63%	68%
*Average Level Functional Impairment	4.5 (needs little assistance)	4.0 (needs some assistance)	3.8 (needs some assistance)
**Average Level Cognitive Impairment	4.0 (slightly impaired)	3.9 (slightly impaired)	3.6 (slightly impaired)
Perceived to Require Institutionalization (caregiver viewpoint)	31%	9%	20%
Perceived to Require/ May Require Institutionalization (social worker viewpoint)	11%	5%	13%
Past Institutionalization Acute Hospital	38%	25%	25%
Average Length of Past. Hospitalization	5 wks.	5.6 wks.	7 wks.

*A score of 1 = unable to perform tasks without a great deal of assistance
A score of 5 = capable of performing tasks without assistance

**A score of: 1 = severe cognitive impairment
5 = no cognitive impairment

TABLE 5 - PRIMARY CAREGIVER CHARACTERISTICS

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
Female	95%	74%	79%
Male	5%	26%	21%
Wife/Husband of Elderly*	34%	48%	31%
Daughter/Son of Elderly*	66%	50%	69%
Daughter-in-Law of Elderly	2%	4%	4%
Other Relative*	10%	5%	12%
Average Age.	61 yrs.	63 yrs.	61 yrs.
Works Full Time	41%	19%	28%
Works Part Time	12%	20%	12%
At Home Full Time	43%	65%	60%
Missing Data re Work Status	5%		
Lives with Elderly	51%	73%	62%
**Average Level Caregiving Skill (caregiver viewpoint)	3.5 (somewhat skilled)	3.5 (somewhat skilled)	3.8 (quite skilled)
**Average Level Caregiving Skill (social work viewpoint)	3.4 (somewhat skilled)	3.4 (somewhat skilled)	3.0 (somewhat skilled)
***Average Level of Knowledge re Elderly's Condition (primary caregiver's viewpoint)	4.1 (quite knowledgeable)	4.0 (quite knowledgeable)	4.2 (quite knowledgeable)

*Since some primary caregivers are caring for more than one elderly relative, calculations will total more than 100%.

**A score of 1 = unskilled
A score of 2 = very skilled

***A score of 1 = poor knowledge
A score of 5 = very knowledgeable

TABLE 6 - PRIMARY CAREGIVER STRESSORS AT INTAKE

N.B. Stressors that were identified by more than 50% of caregivers as being moderately - overwhelmingly stressful are reported below.

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
Worry about Responsibilities of Caregiving	93%	84%	81%
Limitations of Leading Own Life (work, leisure, social life)	85%	79%	75%
Concern about Health of Relative	93%	86%	77%
Concern about Relative's Future	88%	84%	76%
Concern about Own Future	81%	71%	63%
Amount of Time Spent Caregiving	88%	70%	68%
No One to Share Worries With	51%	46%	53%
Difficulty Giving Advice/ Having Advice Accepted	66%	58%	72%
Conflict with Relative	63%	50%	56%
Physical Demands of Caregiving	66%	64%	47%
Conflict with Other Family Members re: Care	42%	38%	37%
Difficulty in Finding Appropriate Services	40%	50%	41%
*Average Rating of Stress re Caring for Elderly	2.1 (major stress)	2.6 (major stress)	3.1 (moderate stress)
**Average Rating re Rewards of Caring for Elderly	3.1 (somewhat (rewarding)	3.4 (somewhat (rewarding)	3.8 (rewardin

*A score of 1 = overwhelmingly stressful
A score of 5 = not stressful

**A score of 1 = not rewarding
A score of 5 = very rewarding

TABLE 7 - PRIMARY CAREGIVER NEEDS (Social Work Viewpoint)

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
Relief from Caregiving Responsibilities	88%	86%	79%
Resolution of Family Conflict/Communication Difficulties	38%	35%	37%
Resolution of Conflict with Elderly Relative/ Communication Difficulties	43%	36%	41%
Emotional Support	48%	62%	78%
Assistance with Future Planning	31%	78%	63%
Financial Planning	7%	9%	3%
Information re Relative's Condition	12%	28%	38%
Information re Care-giving Skills	0	10%	15%
Understanding/Accepting Relative's Personal Choices or Needs	17%	9%	13%
Other	0	3%	0

TABLE 8 - FAMILY CHARACTERISTICS

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
Families without Other Relatives	5%	9%	6%
Families with Out-of-Town Relatives Only	12%	8%	4%
Families with Relatives in Town	83%	84%	90%
No. Family Members Participating in Project	50 (from 24 families: 57% of all families 65% of families with members living in town)	75 (from 40 families: 69% of all families 75% of families with members living in town)	75 (from 42 families: 55% of all families 62% of families with members living in town)
Family Members Completing Intake Questionnaires	38 (from 21 families: 50% of all families 57% of families with members living in town)	N=46 (from 32 families: 55% of all families 60% of families with members living in town)	37 (from 24 families: 32% of all families 35% of families with members living in town)
Relationship to Elderly:			
daughter/son	58%	65%	74%
daughter/son-in-law	10%	27%	29%
brother/sister	0	0	0
grandchild	22%	2	19%
niece/nephew	5%	2%	0
other	5%	4%	8
Lives with elderly relative	83%	84%	74%

TABLE 9 - FAMILY'S KNOWLEDGE

	Group I	Group II	Group III
Average Level of Knowledge re Elderly's Condition (social worker's viewpoint)	3.5 (very good) (N = 42)	3.3 (average) (N = 58)	3.1 (average) (N = 76)
Average Level of Knowledge re Elderly's Condition (family member viewpoint)	3.5 (very good) (N = 38)	3.5 (very good) (N = 46)	3.3 (average) (N = 37)
Average Level of Knowledge re Caregiving Skills (social worker viewpoint)	3.3 (average)	3.2 (average)	3.0 (average)
Average Level of Knowledge re Caregiving Skills (family member viewpoint)	2.7 (somewhat skilled)	2.7 (somewhat skilled)	2.5 (somewhat skilled)
Average Level of Knowledge re Community Resources (social worker viewpoint)	3.0 (average)	2.8 (average)	3.0 (average)

A score of 1 = not at all knowledgeable
A score of 5 = completely knowledgeable

TABLE 10 - FAMILY MEMBER STRESSORS AT INTAKE

	Group I (N = 38)	Group II (N = 46)	Group III (N = 37)
Worry about Responsibilities of Caregiving	63%	69%	70%
Difficulty Giving/Having Advice Accepted by Elderly Relative	42%	58%	53%
Concern about Health of Relative	60%	70%	76%
Lack of Knowledge/Information about Relative's Condition	42%	33%	46%
Concern about Own Future	49%	57%	47%
Concern about Relative's Future	84%	76%	78%
Conflict with Other Family Members re Care	34%	52%	47%
Conflict with Elderly	24%	35%	61%
Time spent in care	32%	42%	57%
Physical demands of care	21%	35%	54%
Limits on living own life	40%	41%	54%
*Average Rating of Stress re Caring for Elderly	3.3 (moderate stress)	3.2 (moderate stress)	2.8 (moderat stress)
**Average Rating re Rewards of Caring for Elderly	3.3 (somewhat rewarding)	3.5 (somewhat rewarding)	2.8 (somewha rewarding)

*A score of 1 = overwhelmingly stressful
A score of 5 = not stressful

**A score of 1 = not rewarding
A score of 5 = very rewarding

TABLE 11 - FAMILY COOPERATION/CONFLICT AT INTAKE

N.B. Calculations represent primary caregiver data. Calculations in brackets represent "other" family member data.

	Group I		Group II		Group III	
	N=41	(N=38)	N=58	(N=46)	N=76	(N=37)
*Average level of cooperation in care of elderly	3.2 some	(3.7) (quite a lot)	3.3 some	(3.7) (quite a lot)	3.2 some	(3.7) (quite a lot)
**Average level of conflict in care of elderly	3.8 not much	(3.4) (not much)	3.8 not much	(3.4) (not much)	3.7 not much	(3.7) (not much)
FAMILY ASSESSMENT MEASURE*	N=25	(N=21)	N=33	(N=28)	N=55	(N=27)
- Family works together on tasks/solving problems	7.5 normal	(7.9) (weak-ness)	5.8 normal	(8.2) (weak-ness)	5.6 normal	(7.3) (normal)
- Family roles are clearly defined	8.2 weak-	(6.5) (normal ness	6.1 normal	(6.7) (normal)	6.2 normal	(6.7) (normal)
- Communication is clear	6.2 normal	(6.7) (normal)	4.5 normal	(7.1) (normal)	4.8 normal	(6.3) (normal)
- Effective communication is appropriate	7.2 normal	(8.0) (weak-ness)	5.3 normal	(8.1) (weak-ness)	5.6 normal	(6.7) (normal)
- Effective involvement is appropriate	5.3 normal	(5.9) (normal)	4.7 normal	(6.3) (normal)	4.4 normal	(5.8) (normal)
- Control is appropriate (no over-control)	3.7 normal	(4.8) (normal)	2.9 strength	(5.5) (normal	3.2 normal	(4.6) (normal)
- Consistent family values	5.1 normal	(5.1) (normal)	3.8 normal	(6.0) (normal)	3.9 normal	(6.0) (normal)

*A score of 1 = no cooperation
A score of 5 = a great deal of cooperation

**A score of 1 = a great deal of conflict
A score of 5 = no conflict at all

***Only data from valid questionnaires have been included here.

TABLE 12 - DECISION-MAKING RE ELDERLY AT INTAKE

N.B. Primary caregiver responses are presented with other family member responses in brackets.

	Group I N=42 (N=38)		Group II N=58 (N=51)		Group III N=76 (N=39)	
Elderly Relative is Consulted	15%	(0)	9%	(8%)	15%	(5%)
Some Family Members are Consulted	44%	(61%)	46%	(47%)	49%	(64%)
All Family Members are Consulted	24%	(32%)	27%	(39%)	19%	(28%)
No One is Consulted	17%	(8%)	18%	(6%)	17%	(3%)
Missing Data	0	(0)	0	(0)	1%	(0)
Final Decisions Made by Primary Caregiver	37%	(5%)	45%	(10%)	45%	(8%)
Final Decision Made by Some Relatives	24%	(58%)	25%	(57%)	28%	(41%)
Final Decisions Made by Elderly Relative	29%	(8%)	16%	(8%)	20%	(31%)
Final Decisions Made by All Relatives	10%	(29%)	14%	(25%)	8%	(21%)

TABLE 13 - FAMILY STRENGTHS (Social Work Viewpoint) AT INTAKE

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
Good Family Relationships/ Communication	56%	47%	14%
Motivated to Change	59%	38%	7%
Well-Informed re Services	26%	2%	4%
Capable, Informed Family	13%	49%	64%
Family has resources	36%	19%	28%
Strong Helping Network	18%	4%	0
Commitment to Elderly Relative	23%	72%	84%
Family supports Primary Caregiver*	not coded	34%	32%
None*	not coded	2%	0
Other*	not coded	2%	1%

*Note: these categories were created after Group I was completed.

TABLE 14 - FAMILY NEEDS (SOCIAL WORK VIEWPOINT) AT INTAKE

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
Relief from Caregiving Responsibilities	51%	28%	25%
Resolution of Family Conflict/Communication Difficulties	34%	59%	48%
Resolution of Conflict/ Communication Difficulties with Elderly	20%	11%	15%
Emotional Support	22%	36%	33%
Specific Future Plans	27%	59%	45%
Financial Planning	5%	0	3%
Information Regarding Elderly's Condition	10%	32%	33%
Understanding Relative's Personal Choices or Needs	27%	11%	17%
Information Regarding Caregiving Skills	0	23%	20%
Other	2%	6%	4%
None	2%	0	0

TABLE 15 - NUMBER OF ASSESSMENTS CONDUCTED

Group I	Group II	Group III
47	58	77
(71% of Referrals)	(62% of Referrals)	(60% of Referrals)

TABLE 16 - COUNSELLING SESSION DATA

N.B. Calculations include all admissions; numbers in brackets represent calculations excluding dropouts.

a) Median No. Counselling Sessions Per Family (Includes Primary Caregivers and/or Other Family Members)

Condition	Group I		Group II		Group III	
	N=42	(N=31)	N=58	(N=41)	N=76	(N=53)
I	3.0	(3.0)	4.0	(5.0)	4.0	(4.0)
II	2.0	(4.0)	3.5	(4.0)	4.0	(4.0)
III	3.0	(4.0)	4.0	(5.0)	4.0	(5.0)

b) Median No. Counselling Sessions Attended by Primary Caregiver

Condition	Group I		Group II		Group III	
	N=42	(N=31)	N=58	(N=41)	N=76	(N=53)
I	3.0	(3.0)	4.0	(4.0)	4.0	(4.0)
II	1.0	(3.0)	3.5	(4.0)	4.0	(4.0)
III	3.0	(3.0)	4.0	(4.5)	4.0	(4.0)

c) Median No. Counselling Sessions Attended by Other Family Members

Condition	Group I		Group II		Group III	
	N=50	(N=26)	N=75	(N=65)	N=75	(N=56)
I	1.0	(1.0)	2.0	(2.0)	1.0	(1.0)
II	0.5	(0.5)	1.6	(1.9)	1.0	(1.0)
III	1.0	(1.0)	2.0	(2.1)	1.0	(3.0)

Counselling Sessions Attended by Elderly Relatives

Elderly relatives rarely if ever attended counselling sessions in Group I.

40% of elderly relatives attended at least one counselling session in Group II.

52% of elderly relatives attended at least one counselling session in Group III.

TABLE 17 - EDUCATION WORKSHOP DATA

N.B. Numbers in brackets represent calculations excluding dropouts.

	Group I	Group II	Group III
No. Workshops Held	6	6	8
No. Outside Resources Used	2	0	0
Average Attendance per Session	10	15	18
Average no. Sessions Attended by Primary Caregiver	1.3 (1.8)	1.0 (1.5)	1.2 (1.5)
Average no. Sessions Attended by Other Family Members	0.6 (0.6)	0.6 (1.0)	0.6 (0.8)
Average no. Topics Covered in Sessions	2.3	3.2	2.8
Topics Covered:			
- information re group organization	no	yes	no
- information re elderly memory deficits and accompanying behaviour problems	yes	yes	yes
- information re support	yes	yes	no
- information re aging process	yes	yes	yes
- information re family involvement	often	yes	no
- specific service information	yes	yes	no
- feelings about available services	yes	no	yes
- feelings about caregiver role	no	yes	yes
- feelings about family involvement	no	yes	no
- feelings about support	no	yes	yes
Topics Planned were Covered	yes	yes	yes

TABLE 18 - MUTUAL SUPPORT GROUP DATA

N.B. Numbers in brackets represent calculations excluding dropouts.

	Group I		Group II		Group III	
Number of Groups Held	19		12		12	
Average Attendance per Session	4		7		7	
Median Number of Sessions Attended by Primary Caregiver	4.0	(5.0)	1.0	(4.0)	2.2	(4.0)
Percentage of "Other" Family Members Attending Sessions:	N=34	(22)	N=24	(17)	N=11	(6)
0 sessions	74%	(64%)	58%	(47%)	55%	(17%)
1 session	6%	(5%)	4	(6%)	0	(0)
2 sessions	3%	(5%)	17%	(18%)	9%	(17%)
3 sessions	3%	(5%)	0	(0)	27%	(50%)
4 sessions	0		0	(0)	9%	(17%)
5 sessions	9%	(14%)	21%	(29%)	0	(0)
6 sessions	6%	(9%)	0	(0)	0	(0)
Average no. Topics Covered per Session	3.8		3.9		3.2	
Topics Planned were Covered	yes		yes		yes	
Topics Covered:						
- information about group purpose and organization	yes		often		yes	
- feeling about group purpose and organization	often		often		often	
- specific information re services	yes				often	
- feelings about available services	yes		often		no	
- specific information re communication/problem solving	yes		yes		often	
- feelings about communication/problem solving	yes		yes		often	

TABLE 18 - MUTUAL SUPPORT GROUP DATA
(continued)

	Group I	Group II	Group III
- feelings about caregiving responsibilities	yes	often	often
- feelings about relationship with elderly relative	often	often	often
- feelings about aging process	yes	no	often
- information about aging process	yes	no	no
- specific information re aging process	no	yes	no
- feelings about behaviour problems	yes	yes	often
- feelings about support	yes	often	often
- feelings about family involvement	yes	often	yes
- information about family involvement	yes	often	no
- specific information re family involvement	no	yes	no

TABLE 19 - PLAN OF CARE DATA

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
No. Developed*	95%	93%	96%
Goal Areas Identified in Plans:			
- to find ways to relieve pressure of constant care of elderly	84%	84%	78%
- family conflict resolution	50%	54%	52%
- resolution of conflict with elderly	45%	44%	41%
- emotional support	68%	88%	92%
- future planning	60%	88%	71%
- financial planning	8%	7%	4%
- information re elderly's condition	47%	35%	41%
- information re caregiving skills	3%	11%	23%
- finding ways to accept relatives choices/needs	13%	9%	18%
- other	3%	0%	0
Average no. of Goals per Family:	3.5	4.1	4.2
Condition I	3.2	4.7	4.2
Condition II	5.5	4.4	3.9
Condition III	4.0	4.1	4.1

*The plans that were not developed are usually dropouts.

TABLE 20 - COMMUNITY RESOURCE INVOLVEMENTS/REFERRALS

a) Involvement at Assessment

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
No. of Families Un-involved with Resources	27 (64%)	33 (57%)	18 (24%)
No. Families Involved with Resources:	15 (36%)	25 (43%)	58 (76%)
- physician	0	3	2
- paramedical	4	7	5
- acute hospital	2	1	6
- community agency	2	10	9
- day care	1	1	7
- Senior Care	0	0	0
- Jewish Home for the Aged	0	1	0
- Baycrest Hospital	6	7	8
- Baycrest intake	2	0	1
- Baycrest Terrace	0	0	2
- Retirement Home	0	0	1
- home for the aged	0	2	2
- Nursing home	0	0	3
- Jewish Family & Child Service	1	3	3
- support group outside Baycrest	0	1	1
- homecare	0	4	6
- wheeltrans	0	0	2
- Branson Hospital	0	0	1
- Mount Sinai Hospital	0	0	1
- other	2	1	1

b) Impediments to Use of Resources (at time of assessment)

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
Resistance	66%	39%	55%
Didn't Know about Resources	12%	25%	5%
Financial Constraints	2%	5%	11%
Other Impediments	10%	2%	1%
No Impediments Identified	2%	29%	27%

TABLE 20 (cont.)

c) Referrals to Community Resources (during program)

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
No. Families Referred	21 (50%)	36 (62%)	39 (51%)
Referral Types:			
- paramedical	1	4	5
- day care	5	9	6
- community agency	7	16	16
- homes for the aged	4	6	4
- Senior Care	8	9	1
- Baycrest Intake	0	0	2
- Support Group Baycrest	0	0	1
- Baycrest Hospital	1	3	9
- Baycrest Terrace	0	0	1
- acute hospital	1	3	2
- Homecare	1	9	7
- senior advocacy centre	2	0	0
- physician	0	0	2
- Jewish Home for Aged	0	0	1
- Retirement Home	0	0	1
- neighbour/friend	0	0	1
- other	0	5	1

d) Referrals to Community Resources (at discharge)

N.B. Dropouts excluded

	Group I	Group II	Group III
No. Families Referred	12 (39%)	26 (63%)	23 (43%)
Referral Types:			
- acute hospital	1	3	1
- day care	1	5	1
- community agency	3	7	7
- Jewish Family & Child Service	2	3	0
- Senior Care	2	4	0
- physician	1	1	0
- nursing home	1	4	0

TABLE 20 (cont.)

d) Referrals to Community Resources (at discharge)

N.B. Dropouts excluded

	Group I	Group II	Group III
No. Families Referred	12 (39%)	26 (63%)	23 (43%)
Referral Types:			
- support group at Baycrest	2	0	0
- Support group outside Baycrest	3	6	4
- paramedical	0	2	1
- Baycrest Hospital	0	0	3
- JHA	0	0	2
- Home for the Aged	0	0	1
- Baycrest Intake	0	0	1
- Homecare	0	0	1
- Senior Advocacy Centre	0	0	1
- Private Psychiatrist	0	0	2
- Other	0	3	1

TABLE 21 - RESPONSIBILITY FOR CAREGIVING TASKS

a) Task Responsibility - Primary Caregiver Viewpoint

	Group I (N = 42)	Group II (N = 58)	Group III (N = 76)
Tasks Not Required by Elderly/ Does them on Own:			
- telephone check ups	42%	61%	44%
- physical care	50%	46%	48%
Tasks Which are Mostly Primary Caregiver Responsibility:			
- visits	59%	38%	30%
- shopping/errands	59%	70%	47%
- attending medical appointments	66%	66%	53%
- transportation	54%	63%	42%
- meal preparation	54%	61%	39%
- household chores	34%	41%	31%
- telephone check ups	30%	25%	20%
Tasks which are Shared with Others:			
- transportation	34%	14%	22%
- visits/companionship	37%	32%	35%
- shopping/errands	34%	21%	24%
- household chores	32%	39%	27%

*There were no tasks where ≥50% of primary caregivers felt that someone else was taking sole responsibility.

TABLE 21 (contd.)

b) Task Responsibility - Family Members Viewpoint

	Group I (N = 42)	Group II (N = 46)	Group III (N = 76)
Tasks Not Required by Elderly/ Does them on Own:			
- physical care	66%	53%	58%
- nursing care	50%	40%	58%
- meal preparation	36%	26%	32%
- telephone check ups	30%	26%	27%
Tasks Which are Mostly Family Member's Responsibility:	None	None	None
Tasks Which are Shared with Others:			
- visits/companionship	71%	80%	72%
- telephone check ups	60%	59%	68%
- transportation	46%	57%	44%
- shopping/errands	39%	46%	41%
Tasks Which are Solely Someone Else's Responsibility:			
- physical care	29%	36%	25%
- nursing care	41%	40%	26%
- medical appointments	44%	51%	30%
- meals preparation	47%	52%	51%

TABLE 22 - QUALITY OF CARE PROVIDED TO ELDERLY
(SOCIAL WORK VIEWPOINT)

	Group I (N = 42)	Group II (N = 58)	Group III (N = 74)
Poor	3%	0	0
Below Average	5%	4%	14%
Average	40%	50%	61%
Very Good	38%	45%	26%
Excellent	15%	2%	0
Missing Data	5%	0	0

TABLE 23 - STAFF TIME DISTRIBUTION

a) Staff Time Distribution (Group I)

	TOTAL HOURS	AVERAGE HOURS
Direct Client Contact		
with admitted families (Counselling)	334 hrs.	8.1 hrs. per family
with referred only families	14 hrs.	0.6 hrs. per family
in educational workshops	9 hrs.	1.5 hrs. per session
in mutual support groups	29 hrs.	1.5 hrs. per session
	386 hrs.	
* Research and Evaluation	129 hrs.	3.2 hrs. per week

*covers 40 weeks of program operations and includes time of entire staff.

b) Staff Time Distribution (Group II)

	TOTAL HOURS	AVERAGE HOURS
Direct Client Contact		
with admitted families (Counselling)	405 hrs.	7.8 hrs. per family
with referred only families	9 hrs.	0.3 hrs. per family
in educational workshops	12 hrs.	2.0 hrs. per session
in mutual support groups	36 hrs.	2.0 hrs. per session
	462 hrs.	
* Research and Evaluation	261 hrs.	7.2 hrs. per week

*covers 36 weeks of program operations and includes time of entire staff.

c) Staff Time Distribution (Group III)

	TOTAL HOURS	AVERAGE HOURS
Direct Client Contact		
with admitted families (Counselling)	652 hrs.	6.7 hrs. per family
with referred only families	6 hrs.	0.4 hrs. per family
in educational workshops	9 hrs.	1.5 hrs. per session
in mutual support groups	29 hrs.	1.5 hrs. per session
	696 hrs.	
* Research and Evaluation	75 hrs.	1.0 hrs. per week

*covers 50 weeks of program operations and includes time of entire staff.

TABLE 24 - CAREGIVER NEEDS BY PROXIMITY TO ELDERLY RELATIVE
(Groups 1-10)

Caregiver Needs	Lives with Relative (N = 57)	Does not live with Relative (N = 50)
Relief from caregiving responsibilities	88%	56%
Resolution of family conflict	30%	42%
Resolution of conflict with relative	37%	56%
Emotional support	68%	72%
Assistance with future planning	47%	36%
Financial planning	5%	4%
Information re relative's condition	32%	30%
Understanding relative's personal choices/needs	9%	30%

**TABLE 25 - CLIENT CHARACTERISTICS:
SPOUSE CAREGIVER VS NON-SPOUSE CAREGIVERS
(Waves 1-10)**

	Spouse (N = 62)	Non-Spouse (N = 101)
Average Age of Primary Caregiver	73 yrs.	55 yrs.
Average Age of Elderly Relative	76 yrs.	81 yrs.
*Average Level of Primary Caregiver Stress	2.3 (major stress)	2.5 (major stress)
Primary Caregiver's Sex		
- Female	74%	86%
- Male	26%	14%
Elderly Relative's Sex		
- Female	32%	81%
- Male	68%	19%
Primary Caregiver Work Status		
- does not work	84%	40%
- full-time work	8%	40%
- part-time work	10%	20%
Living Arrangements		
- PC lives with relative	100%	44%

*A score of 1 = overwhelmingly stressful
A score of 5 = not stressful

TABLE 25 (cont'd)

	Spouse (N = 62)	Non-Spouse (N = 101)
Primary Caregiver Stressors (Moderate-High Stressors):		
- responsibilities of caregiving	90%	88%
- time spent in caregiving	68%	81%
- physical demands of caregiving	63%	58%
- limitations of leading own life	81%	83%
- concern about relative's health	90%	86%
- concern about own future	73%	73%
- concern abour relative's future	84%	86%
- difficulty giving advice/having		
- advice accepted	63%	72%
- conflict with relative	53%	63%
- no one to share worries	18%	57%
- problem finding services	15%	54%
Primary Caregiver Needs:		
- information re relative's condition	35%	24%
- information re caregiving skills	13%	7%
- family conflict/communication resolution	29%	40%
- resolution of conflict with relative	34%	48%
- future planning	61%	57%
- financial planning	8%	5%
- relief from caregiving	85%	82%
- emotional support	60%	68%
- understanding relative's choices	6%	17%
- other	2%	2%

APPENDIX C

SIGNIFICANT OUTCOME ANALYSIS

RESULTS

Table 1a. ANOVA Summary Table for Changes in Stress Levels Due to Family Conflict from Follow-Up I - Follow-Up II, as a Function of Group

Source	df	F	Significance
Between	2	3.94	$p < .02$
Within	81		
Total	83		

Table 1b. N's, Means and Standard Deviations for Follow-Up I - Follow-Up II Difference Scores on Stress Due to Family Conflict, as a Function of Group

Group	N	Mean* Difference	Standard Deviation
I	16	0.31	0.79
II	31	-0.12	0.50
III	37	-0.18	0.62
Total	84	-0.07	0.64

* Positive mean difference scores represent a decrease in stress, negative mean difference scores represent an increase in stress.

Table 1c. N's, Means and Standard Deviations on Stress Due to Family Conflict as Function of Measurement, Timeframe and Group

Timeframe	Group	N	Mean	Standard Deviation
Follow-up I	I	16	3.87	1.19
	II	31	4.42	0.99
	III	39	4.26	0.97
Follow-up II	I	16	4.33	1.18
	II	33	4.33	0.99
	III	41	4.00	1.05

Table 2a. ANOVA Summary Table for Changes in General Stress Levels as a Function of Measurement Timeframe, Treatment Condition and Group

Timeframe	Factor	Source	df	F	Significance
Intake - Follow-Up I	Condition	Between	2	0.23	N.S.
		Within	88		
		Total	90		
Intake - Follow-Up II	Condition	Between	2	1.11	N.S.
		Within	84		
		Total	86		
Follow-Up I - Follow-Up II	Condition	Between	2	0.57	N.S.
		Within	87		
		Total	89		
Intake - Follow-Up I	Group	Between	2	0.10	N.S.
		Within	88		
		Total	90		
Intake - Follow-Up II	Group	Between	2	0.15	N.S.
		Within	84		
		Total	86		
Follow-Up I - Follow-Up II	Group	Between	2	0.84	N.S.
		Within	87		
		Total	89		

Table 2b. N's, Means and Standard Deviations on General Stress Levels as a Function of Measurement Timeframe, Treatment Condition and Group

Timeframe	Factor	N	Mean Difference	Standard Dev.
Intake	Condition I	48	2.21	0.71
	Condition II	51	2.43	0.94
	Condition III	64	2.41	1.02
Follow-up I	Condition I	38	2.24	0.85
	Condition II	29	2.69	1.00
	Condition III	27	2.44	0.89
Follow-Up II	Condition I	39	2.23	0.90
	Condition II	27	2.74	1.02
	Condition III	25	2.32	0.69
Intake	Group I	41	2.12	0.87
	Group II	56	2.59	1.01
	Group III	66	2.30	0.82
Follow-Up I	Group I	18	2.11	0.83
	Group II	33	2.52	1.03
	Group III	43	2.51	0.86
Follow-Up II	Group I	18	2.22	0.81
	Group II	32	2.47	0.98
	Group III	41	2.44	0.90

Table 3a. ANOVA Summary Table for Changes in Stress on Specific Issues from Intake - Follow-Up II, as a Function of Group

Source	df	F	Significance
Between	2	3.73	$p < .03$
Within	61		
Total	63		

Table 3b. N's, Means and Standard Deviations for Intake - Follow-Up II Difference Scores on Stress about Specific Issues, as a Function of Group

Group	N	Mean* Difference	Standard Deviation
I	16	16.25	14.37
II	6	22.00	19.18
III	42	7.95	13.75
Total	64	11.34	15.03

*Mean difference scores are based on the combined scores of 16 stess-related items. Positive mean difference scores represent a decrease in stress.

Table 3c. N's, Means and Standard Deviations in Stress on Specific Issues as a Function of Measurement, Timeframe and Group

Timeframe	Group	N	Mean*	Standard Dev.
Intake	I	24	49.71	8.40
	II	37	52.27	10.65
	III	47	57.28	18.98
Follow-up I	I	24	96.93	39.46
	II	10	118.80	34.17
	III	48	72.23	29.12

*Means are based on the combined scores of 16 stress-related items.

Table 4a. ANOVA Summary Table for Changes in Family Member Involvement in Care, from Intake - Follow-Up II as a Function of Group

Source	df	F	Significance
Between	2	5.20	$p < .01$
Within	105		
Total	107		

Table 4b. N's, Means and Standard Deviations for Intake - Follow-Up II Difference Scores on Family Member Involvement in Care, as a Function of Group

Group	N	Mean* Difference	Standard Deviation
I	21	10.76	11.23
II	37	1.95	9.60
III	50	4.70	9.80
Total	108	4.94	10.41

*Mean difference scores are based on the combined scores on 10 family member involvement items. Positive mean difference scores represent an increase in family involvement.

Table 4c. ANOVA Summary Table for Changes in Family Member Involvement in Care, from Follow-Up I - Follow-Up II as a Function of Group

Source	df	F	Significance
Between	2	3.88	$p < .02$
Within	104		
Total	107		

Table 4d. N's Means and Standard Deviations for Follow-Up I - Follow-Up II Difference Scores on Family Member Involvement in Care as a Function of Group

Group	N	Mean* Difference	Standard Deviation
I	22	4.18	6.59
II	36	.14	2.45
III	49	2.92	7.10
Total	107	2.24	5.99

*Mean difference scores are based on the combined scores on 10 family member involvement items. Positive mean difference scores represent an increase in family involvement.

Table 4e. N's, Means and Standard Deviations on Family Member Involvement in Care as a Function of Measurement, Timeframe and Group

Timeframe	Group	N	Mean*	Standard Dev.
Intake	I	26	22.15	8.22
	II	37	20.59	7.64
	III	51	18.02	9.68
Follow-Up I	I	23	16.00	10.17
	II	36	19.31	10.16
	III	50	16.34	10.40
Follow-up II	I	26	11.15	9.33
	II	37	18.65	10.53
	III	50	13.32	9.72

*Means are based on the combined scores on 10 family member involvement items.

*The lower the mean the greater the family member involvement in care.

Table 5a. ANOVA Summary Table for Changes in Awareness of Community Resources (Social Work Viewpoint) from Intake - Discharge as a Function of Treatment Condition

Source	df	F	Significance
Between	2	3.24	$p < .04$
Within	110		
Total	112		

Table 5b. N's, Means and Standard Deviations for Intake - Discharge Difference Scores on Awareness of Community Resources (Social Work Viewpoint), as a Function of Treatment Condition

Treatment Condition	N	Mean* Difference	Standard Deviation
I	46	0.61	0.88
II	31	1.00	0.72
III	31	0.97	0.66
Total	108	0.83	0.79

*Positive mean difference scores represent an increase in awareness of community resources.

Table 6a. Status of Elderly Relatives at Discharge as a Function of Treatment Condition

	Condition I (N = 55)	Condition II (N = 46)	Condition III (N = 33)
Same Home	85%	83%	94%
Changed Home	4%	4%	0%
Acute Care Hospital	5%	4%	3%
Institutionalized	2%	4%	3%
Died	4%	4%	0%

Table 6b. Status of Elderly Relatives at Follow-Up III as a Function of Treatment Condition

	Condition I (N = 45)	Condition II (N = 27)	Condition III (N = 25)
Same Home	71%	70%	76%
Changed Home	11%	7%	8%
Acute Care Hospital	16%	7%	0%
Institutionalized	2%	11%	12%
Died	0%	4%	4%

Table 7a. Changes Affecting Caregiving Role at Discharge (N = 56, 49% of all families)

Caregiver Got Sick	21%
Elderly relative Got Worse	14%
Other Family Member Got Sick	11%
Reduction in Need to Care for Other Family Members	14%
Vacations	5%
Other Positive Reasons	9%
Other Negative Reasons	11%

Table 7b. Changes Affecting Caregiving Role at Follow-Up III (N = 77, 68% of all families)

Caregiver Got Sick	16%
Elderly relative Got Worse	22%
Other Family Member Got Sick	4%
Financial Problems	3%
Reduction in Need to Care for Other Family Members	4%
Vacations	8%
Family Members Got More Involved	7%
Other Positive Reasons	33%
Other Negative Reasons	30%

Table 8a. Percentage of Treatment Goals Achieved per Family as a Function of Treatment Condition (as Recorded by Social Workers)

Achievement Rate of Goals	Condition I (N = 49)	Condition II (N = 39)	Condition III (N = 37)
0 - 33%	79%	79%	49%
34 - 67%	12%	18%	41%
68 - 100%	8%	3%	11%

Table 8b. Percentage of Treatment Goals Achieved for Family as a Function of Wave Group (as Recorded by Social Workers)

Achievement Rate of Goals	Group I	Group II	Group III
0 - 33%	65%	65%	77%
34 - 67%	23%	24%	21%
68 - 100%	13%	10%	1%

Table 9. Types of Treatment Goals Achieved (As Recorded by Social Workers)

Goal Area	% Achieved	% Somewhat Achieved	% Not Achieved
Emotional Support	44%	55%	2%
Relief from Caregiving Responsibility	26%	64%	10%
Future Planning	25%	75%	1%
Decreasing Family Conflict	11%	56%	33%
Decreasing Conflict with Elderly	9%	86%	5%
Providing Information Re Relatives' Condition	30%	61%	9%

Table 10. Utility of Treatment, Components (As Reported by Caregivers)

a.) **Utility of Counselling Sessions (N = 92)**

Not Useful at all	3%
A Little Bit Useful	9%
Somewhat Useful	20%
Quite Useful	32%
Very Useful	37%

b.) **Utility of Educational Workshops (N = 46)**

Not Useful at All	11%
A Little bit Useful	28%
Somewhat Useful	22%
Quite Useful	5%
Very Useful	13%

c.) **Usefulness of Mutual support Groups (N = 26)**

Not Useful	0%
A Little bit Useful	19%
Somewhat Useful	23%
Quite Useful	23%
Very Useful	35%

Table 11. Most Helpful Aspects of the Program as a Function of Treatment Condition

	Condition I (N = 31)	Condition II (N = 24)	Condition III (N = 26)
Counselling Sessions	19%	79%	50%
Talking to Someone	36%	4%	8%
Nothing Was Useful	23%	0%	0%
Info. Re Services	7%	4%	4%
Emotional Support/Relief	7%	8%	4%
Support Groups	N/A	N/A	19%
Educational Workshops	N/A	4%	8%
Other	23%	4%	23%

Table 12a. Percentage of Caregivers Who Would Recommend the Program to Others, as a Function of Treatment Condition

	Condition I (N = 36)	Condition II (N = 30)	Condition III (N = 27)
Would Not Recommend	14%	7%	0%
Might Recommend	6%	7%	7%
Would Recommend	69%	87%	93%

Table 12b. Percentage of Caregivers Who Would Recommend the Program to Others, as a Function of Group

	Group I (N = 19)	Group II (N = 29)	Group III (N = 45)
Would Not Recommend	11%	14%	2%
Might Recommend	16%	14%	4%
Would Recommend	74%	72%	96%

Volume

2

EVALUATION OF BAYCREST CENTRE'S CARING FOR THE CAREGIVERS DEMONSTRATION PROJECT

VOLUME II

Research Protocol and Measures

A Final Report to the
Ontario Ministry of Community and Social Services

The ARA Consulting Group Inc.
October 1990

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ITEM 1

CARING FOR THE CAREGIVERS

PROTOCOL AND MEASURES

This document describes the accompanying measures designed to collect data for the process and outcome evaluation of Baycrest's "Caring for the Caregivers" project. This protocol will refer to each one of the measures in turn, describing its place in the evaluation process. The attached instruments are organized into two sections: General Project Information/ Recording Systems (including master schedules and timesheets) and the Clinical File (which includes all forms for each individual family).

General Project Information/Recording Systems

1. **Administrative Activity Timesheet:** This form was designed to collect data on staff time spent in administrative activity for each of the various program components, as well as for the research/evaluation process. The form provided data for the transferability evaluation components of the project. It was completed by social work staff on a regular basis.

2. **Master Schedule:** This form collected information on the time spent on each individual family as they progressed through the project, and provided a dated timeline for each family. It indicated how many family members participated in each activity. The form provided data for process and transferability evaluation components of the project. It was completed by social work staff on a regular basis.

3. **Meeting Sheet:** This form collected data on topics covered and attendance at educational workshops and mutual support groups and provided process evaluation data. It was completed by social work staff following each meeting.

4. **Random Assignment - Baycrest:** This form was the means by which ARA made random assignment of families to each treatment condition offered by Baycrest during

a given wave. In order to find out which treatment a particular family was assigned to, Baycrest staff telephoned ARA after the initial appointment was made with the family. If the family agreed to participate in the project, then they were told which treatment (service) they were to receive. If they refused, the next family was interviewed, and assigned to a treatment according to the next assigned treatment, indicated on the list. At the end of the wave, additional families were interviewed in sufficient numbers to fill the refused treatment conditions, in the order of the condition originally refused.

Clinical File

1. **Enquiry re Service**: This form was an extension of the form currently used by Baycrest Intake when families make a request for service by telephone. In addition to demographic and referral data, information was collected on whether or not the family qualified for the caregiver study. The form was completed by the Project Director. Based on the information contained on these forms the Project Director selected families who met the initial criteria for inclusion in the study and arranged interviews for these families.

2. **Face Sheet**: This form was filled out by Caring for the Caregivers social work staff as a summary measure for each family's file. When this form was completed during/after the assessment interview, a 6-digit Baycrest reference number (with - 5 as the last digit) was assigned to the family, as well as a 3-digit Caregiver project number (from 001 to 178). This form was updated as necessary, by Project staff.

3. **Consent Form**: After the social work staff explained the Caregiver Project, and the need to participate in the evaluation, family members were asked to sign a consent form. This process took place at the beginning of the assessment interview.

4. **Primary Caregiver Questionnaire - Intake**: This paper and pencil measure was designed to collect information necessary to answer research questions relevant to the outcome evaluation. The social worker first identified the primary caregivers. This form was administered with the assistance of the Caregiver project social work staff as necessary, at the assessment interview.

   It should be noted that questions 7c, 7d and 8m in this questionnaire pertain to "family" conflict and cooperation. If the Primary Caregiver had no family, the social worker ensured that the respondent did not answer these items.

5. **Family Member Questionnaire - Intake**: This paper and pencil measure was filled out by each family member present at the same time as the primary caregiver was completing the parallel measure, at the assessment interview. The social worker provided assistance in completing the form as required. The form provided data relevant to outcome evaluation.

6. **Assessment Interview**: This measure was completed during or immediately following the assessment interview with the family by the Caregiver Project social work staff. This information was used for process evaluation and outcome evaluation purposes.

7. **Family Assessment Measure (General Scale)**: This standardized paper and pencil measure was completed by each family member present at the first counselling session. Social work staff provided assistance in completing these forms, as required. The measure provided data relevant to outcome evaluation questions. This measure was not administered to surrogate primary caregivers or to a spouse who was the only family member providing care.

   The Family Assessment Measure (FAM) is a 50-item measure designed to provide factor scores on a number of dimensions, including:

- Task Accomplishment - the degree to which basic family tasks are identified and flexible solutions applied;
- Role Performance - the degree to which family members agree on role definitions within the family and are able to develop new roles as appropriate;
- Communication - the degree to which communications are clear and direct, leading to mutual understanding;
- Affective Expression - the degree to which the range and intensity of feelings are expressed;
- Affective Involvement - the degree to which the emotional needs are met within the family in a nurturant, supportive environment;
- Control - the degree to which there is an appropriate degree of flexibility or predictability in style of control exerted; and
- Value and Norms - the degree of agreement or conflict within the family on values, and the fit between family values and society's values.

Although scores on these factors do not directly parallel the research questions of this project, there is considerable overlap in the content of the scales and the general issue of family functioning along central dimensions. Good validity and reliability statistics have been reported (above .80) and Canadian norms are available.

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*Skinner, H.A., Steinhauer, P.D. and Santa-Barbara, J. The Family Assessment Measure, Canadian Journal of Community Mental Health, Vol. 2, #2, 1983, pp. 91-105.

8. **Plan of Care:** This instrument outlines the goals, objectives and strategies adopted as part of the plan of care for the families. It was completed and updated by social work staff, during the time the family was participating in the project, and provided data for addressing process and outcome evaluation questions.

9. **Notes from Counselling Sessions:** These notes were completed by social work staff and included in the clinical file for the convenience of the project staff, although they did not contribute to the evaluation.

10. **Discharge Interview:** This measure was completed by Caregiver Project staff upon discharge of the family from the project (upon completion of planned program services, or upon early termination, if possible). Information was used for process evaluation and outcome purposes.

11. **Research Reminder Letter:** This letter was distributed to family members present at the Baycrest discharge interview. It was designed to remind caregivers of their commitment to participate in the research effort and to encourage them to arrange follow-up interviews with ARA staff in a timely fashion.

12. **Primary Caregiver Questionnaire - Follow-UP I:** This paper and pencil form was filled out with the assistance of ARA research staff as soon as possible, following discharge from the program. Interviews and form completion occurred at the family's home, where feasible. Information was used for the outcome evaluation.

    It should be noted that questions 7c, 7d and 8m in this questionnaire pertain to "family" conflict and cooperation. If the Primary Caregiver had no family, ARA staff ensured that the respondent did not answer these items.

13. **Family Member Questionnaire - Follow-UP I:** This paper and pencil form was filled out by family members as soon as possible after discharge from the project. ARA research staff assisted family members in completing the questionnaire at the home interview. Information was used for outcome evaluation purposes.

14. **Family Assessment Measure - General:** This paper and pencil measure was once again completed by all family members post discharge, with the assistance of ARA research staff, at the home interview. Information was used for the outcome evaluation. This measure was not administered to surrogate primary caregivers or to a spouse who was the only family member providing care.

15. **Primary Caregiver Follow-Up II Interview:** This form was the basis of a telephone interview with the primary caregiver conducted by ARA research staff approximately 3-months after the Follow-Up I interview. It provided data for outcome evaluation purposes.

    It should be noted that question 8m in this questionnaire pertains to "family" conflict. If the Primary Caregiver had no family, ARA staff ensured that the respondent did not answer this item.

16. **Follow-Up III Interview:** This form was completed by Baycrest social work staff during or following a 6-month post discharge follow-up interview with the family. It provided data for outcome evaluation purposes.

GENERAL PROJECT INFORMATION/
RECORDING SYSTEMS

ITEM 2

ADMINISTRATIVE ACTIVITY TIMESHEET

WEEK OF: _____

STAFF: _____

INSTRUCTIONS - Indicate time spent on each activity in 15 minute time blocks - i.e. put a checkmark for each 15 minute time period.

	DAY 1	DAY 2	DAY 3	DAY 4	DAY 5	TOTAL
GENERAL PROGRAM ADMINISTRATION (e.g., team meetings)						
MUTUAL SUPPORT GROUP ADMINISTRATION (i.e., meeting preparation, phone calls)						
EDUCATIONAL GROUP ADMINISTRATION (COND. II, III, II & III) (i.e., preparation phone calls)						
RESEARCH/EVALUATION (Does not include process evaluation recording)						

ITEM 3

MASTER SCHEDULE: WAVE #1 _____

FAMILY # _____ CONDITION # _____ TOTAL TIME PER FAMILY _____	ASSESSMENT	COUNSELLING #1	#2	#3	#4	TELE-PHONE	EDUCATION WORKSHOP #1	#2	MUTUAL SUPPORT GROUP #1	#2	#3	#4	#5	#6	#7	#8	DISCHARGE INTERVIEW	6-MONTH FOLLOW-UP
PRIMARY CAREGIVER																		
OTHER FAMILY 1. 2. 3. 4. 5.																		
ELDERLY PERSON																		

FAMILY # _____ CONDITION # _____ TOTAL TIME PER FAMILY _____	ASSESSMENT	COUNSELLING #1	#2	#3	#4	TELE-PHONE	EDUCATION WORKSHOP #1	#2	MUTUAL SUPPORT GROUP #1	#2	#3	#4	#5	#6	#7	#8	DISCHARGE INTERVIEW	6-MONTH FOLLOW-UP
PRIMARY CAREGIVER																		
OTHER FAMILY 1. 2. 3. 4. 5.																		
ELDERLY PERSON																		

FAMILY # _____ CONDITION # _____ TOTAL TIME PER FAMILY _____	ASSESSMENT	COUNSELLING #1	#2	#3	#4	TELE-PHONE	EDUCATION WORKSHOP #1	#2	MUTUAL SUPPORT GROUP #1	#2	#3	#4	#5	#6	#7	#8	DISCHARGE INTERVIEW	6-MONTH FOLLOW-UP
PRIMARY CAREGIVER																		
OTHER FAMILY 1. 2. 3. 4. 5.																		
ELDERLY PERSON																		

FAMILY # _____ CONDITION # _____ TOTAL TIME PER FAMILY _____	ASSESSMENT	COUNSELLING #1	#2	#3	#4	TELE-PHONE	EDUCATION WORKSHOP #1	#2	MUTUAL SUPPORT GROUP #1	#2	#3	#4	#5	#6	#7	#8	DISCHARGE INTERVIEW	6-MONTH FOLLOW-UP
PRIMARY CAREGIVER																		
OTHER FAMILY 1. 2. 3. 4. 5.																		
ELDERLY PERSON																		

ITEM 4

MEETING SHEET

WAVE NO.: _____

TYPE OF MEETING: EDUCATIONAL WORKSHOP ☐

MUTUAL SUPPORT GROUP ☐

DATE OF MEETING: _____

LENGTH OF MEETING: _____

OUTSIDE RESOURCE PEOPLE PARTICIPATING (ORGANIZATIONAL AFFILIATION)

WHO ATTENDED: NAMES

TOPICS PLANNED:

1.

2.

3.

TOPICS COVERED:

1.

2.

3.

COMMENTS ABOUT MEETING:

ITEM 5

RANDOM ASSIGNMENT

Wave 1 (C, CEMS)(6,5)			Wave 2 (CE, CEMS)(5,6)			Wave 3 (C, CEMS) (6,5)		
		FAMILY NAME			FAMILY NAME			FAMILY NAME
1.	CEMS		1.	CE		1.	CEMS	
2.	CEMS		2.	CEMS		2.	CEMS	
3.	C		3.	CE		3.	C	
4.	CEMS		4.	CE		4.	C	
5.	CEMS		5.	CEMS		5.	C	
6.	C		6.	CEMS		6.	CEMS	
7.	CEMS		7.	CEMS		7.	C	
8.	C		8.	CEMS		8.	CEMS	
9.	CEMS		9.	CE		9.	C	
10.	C		10.	CE		10.	CEMS	
11.	C		11.	CEMS		11.	C	
12.	C		12.	CEMS		12.	CEMS	
13.	CEMS		13.	CE		13.	C	
14.	C		14.	CEMS		14.	CEMS	
15.	CEMS		15.	CEMS		15.	C	
16.	CEMS		16.	CE		16.	C	
17.	C		17.	CE		17.	CEMS	
18.	CEMS		18.	CEMS		18.	CEMS	
19.	C		19.	CEMS		19.	CEMS	
20.	CEMS		20.	CE		20.	C	
21.	C		21.	CE		21.	CEMS	
22.	C		22.	CEMS		22.	C	

C - Counselling Only

CE - Counselling and Education

CEMS - Counselling, Education and Mutual Support

CLINICAL FILE

Content:

Enquiry Re Service

* Face Sheet

Consent Form

Intake Research Measures

* Assessment Interview

Plan Of Care

Notes From Counselling Sessions

* Discharge Interview

Research Reminder Letter

Follow - Up I Research Measures

Follow-Up II Research Measure

* Follow-Up III Interview

* asterisks beside questions on Face Sheet, Assessment Interview, Discharge Interview and Follow-Up III Interview, indicate that the question was to be used for process or outcome evaluation purposes. Questions without an asterisk were for clinical information purposes only.

ITEM 6

BAYCREST CENTRE FOR GERIATRIC CARE

Enquiry Re Service

J.H.A.:_____ Hospital:_____ Day Care:_____ Residence:_____ Caregiver Project:_____

Date:_____ Taken By:_____

Regarding:_____ Ages:_____

Address:_____ Tel. No.:_____

Where Now?_____

Referrant:_____ Relationship:_____

Address:_____ Tel. No.:_____
(Home) (Business)

Reasons For Enquiring:

Caregiver Study:

If enquiring about caregiver project where did they hear about it? _____

Study Criteria	Yes	No
1. Over 60 years of age		
2. Living in community		
3. There is an identified family/surrogate caregiver involved		
4. Caregiver speaks English		
5. Interested in considering caregiver project		
6. Institutional placement is unlikely to occur within next 6 months		

---

(1) Send/Give Social Information Form To:_____
(Name)

_____
(Address)

Date Form Sent/Given:_____ By:_____ Strip Made By: _____

(2) Send/Give Medical Information Form To: Physician:_____
(Name)

_____
(Address)

ITEM 7

FACE SHEET

1. APPLICANT'S NAME:_____ CLIENT NO.:_____

ADDRESS:_____ BIRTHDATE:_____

_____ TEL:_____ BIRTHPLACE:_____

ARRIVAL IN CANADA:_____ ONTARIO:_____ TORONTO:_____ CANADIAN CITIZEN YES _____ NO _____

SPOUSE, CHILDREN AND/OR INTERESTED RELATIVES:

NAMES:_____ ADDRESS:_____ TELEPHONE:_____

_____

_____

_____

_____

_____

_____

PLEASE INDICATE (*) WHEN RELATIVE IS NAMED AS PRIMARY CAREGIVER.

*2. ☐ FAMILY IS SCREENED OUT OF CAREGIVER PROJECT FOLLOWING ASSESSMENT

REASONS: 1. Do not agree to details of project. Specify Why: _____ ☐

_____

2. Do not have time to participate ☐

3. Would be disruptive in Mutual Support Groups ☐

4. Other (specify) _____ ☐

*

☐ FAMILY IS ADMITTED TO PROJECT INTO:

1. Condition #1 - Counselling ☐

2. Condition #2 - Counselling and Educational Workshops ☐

3. Condition #3 - Counselling and Educational Workshops and Mutual Support Groups ☐

3. SOC. INS. NO.:_____ BLUE CROSS NO.:_____

O.A.S. NO.:_____ O.H.I.P. NO.:_____

ONT. PRIVILEGE CARD NO.:_____ EXT. CARE CERT. NO.:_____

*4. COLLATERAL:

	AGENCY	CONTACT		
AT TIME OF ASSESSMENT:				
			RECRUITER	COORDINATOR
REFERRALS MADE DURING PROGRAM:				
REFERRALS MADE ON DISCHARGE:				

5. SIGNIFICANT DATES:

ENQUIRY	REGISTRATION	CLOSED	TRANSFERRED	ADMITTED J.H.A.	ADMITTED TERRACE

ASSIGNED	FIRST CONTACT	FIRST SOCIAL WORK INTERVIEW

JOINED: DAY CARE
WAGMAN C.

MEDICAL BOARD APPROVAL:

ADMISSIONS COMMITTEE APPROVAL:

*6. ☐ FAMILY FAILED TO COMPLETE PROGRAM

REASONS: _____

_____

_____

_____

_____

7. SIGNIFICANT DOCUMENTS ON FILE - E.G., SUMMARIES, REPORTS, ETC.

_____ _____

_____ _____

_____ _____

_____ _____

_____ _____

_____ _____

ITEM 8

CONSENT TO PARTICIPATE IN RESEARCH

Baycrest's "Caring for the Caregivers" program has been designed to provide advice and assistance to families who are providing care to elderly relatives. The services which will be provided by Baycrest include counselling, educational workshops in caregiving skills, and mutual support groups for families. Not all families will be participating in all services.

In order for Baycrest to understand the needs of caregiving families, a research study of all families participating in the project will be conducted by a research firm, A.R.A. Consultants, on behalf of Baycrest. The purpose of this study is to help Baycrest evaluate and refine its services as necessary to better serve the needs of caregiving families. It is necessary to ask all families to participate in the research project as a condition of taking part in the "Caring for the Caregivers" project.

As part of this research study, all your family members will be asked to fill out some questionnaires when they first meet with Baycrest. This information will be shared between Baycrest staff and A.R.A. Consultants. After taking part in the "Caring for the Caregivers" project, your family will again be asked to fill out questionnaires, and will be interviewed by an A.R.A. researcher about the project. This information will not be shared with Baycrest staff. You will be contacted briefly by telephone in the year following your participation in the project to follow up on the status of your elderly relative.

All information that you provide will be **completely confidential**, and your responses will never be discussed with any other family member. A final report will be written, which will summarize results from **all** individuals taking part in the project. No names will appear in the report. Any information you provide will be combined with information from other families so that it will not be possible to identify any particular family.

By signing this form, you agree to participate in the research/evaluation study, with the understanding that all of your responses will remain **entirely confidential.**

Thank you for your assistance. Your responses are important in assisting Baycrest to improve its services to the community.

NAME	DATE
NAME	DATE
NAME	DATE

ITEM 9

Client No._____

Date: _____

Completed by: _____

PRIMARY CAREGIVER QUESTIONNAIRE

INTAKE

The following questions are designed to identify the needs and sources of stress for people who provide care for a relative or spouse. Baycrest Centre is interested in understanding the needs of families caring for elderly relatives and spouses in the community, so that programs can be designed to meet these needs more effectively. Your help is appreciated.

Caregiving Arrangements

1. What is your relationship to your relative?
"I am my relative's ... (Circle number)

1	Wife	7	Granddaughter
2	Husband	8	Grandson
3	Daughter	9	Niece
4	Son	10	Nephew
5	Daughter-in-Law	11	Other (describe)
6	Son-in-Law		_____

2. At present, where is your relative living? (Circle number)

1 Independently (in their own home or apartment)

2 Semi-independently (e.g., back and forth between their home and mine)

3 With me (in my home or theirs)

4 In a hospital (specify name) _____

5 Other (specify) _____

3. a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

1 No

2 Yes (specify name of institution) _____

(for how long) _____

b) Do you believe your relative needs to be in a hospital or institution of some kind? (Circle number)

1 No

2 Yes (specify name or kind of institution) _____

4. Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	

5. For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

6. Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

7. Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

8. Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

9. How do you and your family make decisions about the care of your relative? (You may circle more than one number)

<u>Who is consulted?</u>

1. No one
2. My relative him/herself
3. Some family members
4. All family members

<u>Who makes the **final** decisions?</u>

1. You (primary caregiver)
2. My relative him/herself
3. Some family members
4. All family members

ITEM 10

Client No. _____

Date: _____

Completed by: _____

FAMILY MEMBER QUESTIONNAIRE

INTAKE

The following questions are designed to identify the needs and sources of stress for the family members of an elderly relative. Baycrest Centre is interested in understanding the needs of families caring for elderly relatives in the community, so that programs can be designed to meet these needs more effectively. Your help is appreciated.

Caregiving Arrangements

1. What is your relationship to your elderly relative?
   "I am my elderly relative's ... (Circle number)

1	Wife	7	Granddaughter
2	Husband	8	Grandson
3	Daughter	9	Niece
4	Son	10	Nephew
5	Daughter-in-Law	11	Other (describe)
6	Son-in-Law		_____

2. Are you currently living with your elderly relative? (Circle number)
   1 No
   2 Yes

3. Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	

4. For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your elderly relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

5. Care of an elderly relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your elderly relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your elderly relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

6. Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your elderly relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your elderly relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your elderly relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your elderly relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

7. Which of the following would you describe as a source of stress for **you** in caring for your elderly relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about heaith condition of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about elderly relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to elderly relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

8. How do you and your family make decisions about the care of your elderly relative? (You may circle more than one number)

Who is consulted?

1. No one
2. Elderly relative
3. Some family members
4. All family members

Who makes the final decisions?

1. You (primary caregiver)
2. Elderly relative
3. Some family members
4. All family members

ITEM 11

ASSESSMENT INTERVIEW FORMAT

Date of Interview:_____

Client No.:_____

***I. Demographics**

1. Names of Family Members	Age	Sex	Work Status	Relationship
_____	___	___	_____	_____
_____	___	___	_____	_____
_____	___	___	_____	_____
_____	___	___	_____	_____
_____	___	___	_____	_____

(*Note with * those family members present at interview.)

II. Elderly Person (name)_____

*1. Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4 Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4 Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4 Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2. Degree of Functional Impairment:

Ability to Walk:

Immobile	Wheelchair	Requires Assistance on Stairs, etc.	Independent With Cane, Crutches, or Walker	Fully Ambulatory
1	2	3	4	5

Eating:

Extensive Assistance/ Uncooperative	Extensive Assistance/ Cooperative	Moderate Assistance/ Cooperative	Minor Assistance	Without Assistance
1	2	3	4	5

Dressing:

Has to be dressed/ Uncooperative	Has to be dressed/ Cooperative	Assistance Only	Supervision Only	Can dress Self Appropriately
1	2	3	4	5

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3. Need For Institutionalization:

	Yes	No
Presently	____	____
In Six Months	____	____

Elderly Person (name)_____

*1.2 Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4 Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4 Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4 Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2.2 Degree of Functional Impairment:

Ability to Walk:

Immobile 1	Wheelchair 2	Requires Assistance on Stairs, etc. 3	Independent With Cane, Crutches, or Walker 4	Fully Ambulatory 5

Eating:

Extensive Assistance/ Uncooperative 1	Extensive Assistance/ Cooperative 2	Moderate Assistance/ Cooperative 3	Minor Assistance 4	Without Assistance 5

Dressing:

Has to be dressed/ Uncooperative	Has to be dressed/ Cooperative	Assistance Only	Supervision Only	Can dress Self Appropriately
1	2	3	4	5

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3.2 Need For Institutionalization:

	Yes	No
Presently	_____	_____
In Six Months	_____	_____

Elderly Person (name)_____

*1.3 Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4	Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4	Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4	Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2.3 Degree of Functional Impairment:

Ability to Walk:

Immobile 1	Wheelchair 2	Requires Assistance on Stairs, etc. 3	Independent With Cane, Crutches, or Walker 4	Fully Ambulatory 5

Eating:

Extensive Assistance/ Uncooperative 1	Extensive Assistance/ Cooperative 2	Moderate Assistance/ Cooperative 3	Minor Assistance 4	Without Assistance 5

Dressing:

Has to be dressed/ Uncooperative 1	Has to be dressed/ Cooperative 2	Assistance Only 3	Supervision Only 4	Can dress Self Appropriately 5

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3.3 Need For Institutionalization:

	Yes	No
Presently	_____	_____
In Six Months	_____	_____

III. Family Background

IV. Primary Caregiver

*1. What are the needs of the primary caregiver?

(a) _____

_____

(b) _____

_____

(c) _____

_____

(d) _____

_____

2. Is the caregiver socially isolated?

_____

_____

_____

_____

3. What roles do neighbours/friends play in caregiving?

_____

_____

_____

_____

4. What specific stresses are faced by the primary caregiver (privacy, need for relief, ability to work, etc.)?

_____

_____

_____

_____

V. Family Needs/Dynamics

1. How are other family members involved in caregiving?

*2. What are the family's needs?

(a)

(b)

(c)

(d)

3. What is the nature of the family relationship?

4. Over what issues is there stress and conflict?

5. How are family decisions made about care of the elderly relative(s)?

_____

_____

_____

_____

*6. What are the strengths of the family?

(a) _____

_____

(b) _____

_____

(c) _____

_____

(d) _____

_____

VI. Knowledge

*1. What is the family's level of knowledge/understanding of the elderly person's(s) condition?

Poor		Average		Excellent
1	2	3	4-	5

*2. What is the family's level of knowledge/understanding of caregiving skills?

Poor		Average		Excellent
1	2	3	4	5

*3. What is the level of awareness of community resources on the part of the family?

Poor		Average		Excellent
1	2	3	4	5

What problems/barriers have there been in the family's use of community resources?

_____

_____

_____

_____

*4. Social Worker: Please rate your opinion of how competent the primary caregiver is in the caregiving role.

Not at all competent				Very Competent
1	2	3	4	5

*5. What is the general quality of care provided for the elderly person(s)?

Poor		Average		Excellent
1	2	3	4	5

Comments:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

ITEM 12

CLIENT NO._____

DATE: _____

COMPLETED BY: _____

FAMILY ASSESSMENT MEASURE

GENERAL SCALE

DIRECTIONS

ON THE FOLLOWING PAGES YOU WILL FIND 50 STATEMENTS ABOUT YOUR FAMILY **AS A WHOLE.** PLEASE READ EACH STATEMENT AND DECIDE HOW WELL THE STATEMENT DESCRIBES YOUR FAMILY.

IF YOU STRONGLY AGREE WITH THE STATEMENT THEN CIRCLE THE LETTERS "SA" BESIDE THE ITEM NUMBER; IF YOU AGREE WITH THE STATEMENT THEN CIRCLE THE LETTER "A".

IF YOU DISAGREE WITH THE STATEMENT THEN CIRCLE THE LETTER "D"; IF YOU STRONGLY DISAGREE THEN CIRCLE THE LETTERS "SD".

IF THE STATEMENT IS NOT APPLICABLE THEN CIRCLE THE LETTERS "NA"

PLEASE CIRCLE **ONLY ONE** LETTER (RESPONSE) FOR EACH STATEMENT. ANSWER EVERY STATEMENT, EVEN IF YOU ARE NOT COMPLETELY SURE OF YOUR ANSWER.

1.	WE SPEND TOO MUCH TIME ARGUING ABOUT WHAT OUR PROBLEMS ARE.	SA	A	D	SD	NA
2.	FAMILY DUTIES ARE FAIRLY SHARED.	SA	A	D	SD	NA
3.	WHEN I ASK SOMEONE TO EXPLAIN WHAT THEY MEAN, I GET A STRAIGHT ANSWER.	SA	A	D	SD	NA
4.	WHEN SOMEONE IN OUR FAMILY IS UPSET, WE DON'T KNOW IF THEY ARE ANGRY, SAD, SCARED OR WHAT.	SA	A	D	SD	NA
5.	WE ARE AS WELL ADJUSTED AS ANY FAMILY COULD POSSIBLY BE.	SA	A	D	SD	NA
6.	YOU DON'T GET A CHANCE TO BE AN INDIVIDUAL IN OUR FAMILY.	SA	A	D	SD	NA
7.	WHEN I ASK WHY WE HAVE CERTAIN RULES, I DON'T GET A GOOD ANSWER.	SA	A	D	SD	NA
8.	WE HAVE THE SAME VIEWS ON WHAT IS RIGHT AND WRONG.	SA	A	D	SD	NA
9.	I DON'T SEE HOW ANY FAMILY COULD GET ALONG BETTER THAN OURS.	SA	A	D	SD	NA
10.	SOME DAYS WE ARE MORE EASILY ANNOYED THAN ON OTHERS.	SA	A	D	SD	NA
11.	WHEN PROBLEMS COME UP, WE TRY DIFFERENT WAYS OF SOLVING THEM.	SA	A	D	SD	NA

12.	MY FAMILY EXPECTS ME TO DO MORE THAN MY SHARE.	SA	A	D	SD	NA
13.	WE ARGUE ABOUT WHO SAID WHAT IN OUR FAMILY.	SA	A	D	SD	NA
14.	WE TELL EACH OTHER ABOUT THINGS THAT BOTHER US.	SA	A	D	SD	NA
15.	MY FAMILY COULD BE HAPPIER THAN IT IS.	SA	A	D	SD	NA
16.	WE FEEL LOVED IN OUR FAMILY.	SA	A	D	SD	NA
17.	WHEN YOU DO SOMETHING WRONG IN OUR FAMILY, YOU DON'T KNOW WHAT TO EXPECT.	SA	A	D	SD	NA
18.	IT'S HARD TO TELL WHAT THE RULES ARE IN OUR FAMILY.	SA	A	D	SD	NA
19.	I DON'T THINK ANY FAMILY COULD POSSIBLY BE HAPPIER THAN MINE.	SA	A	D	SD	NA
20.	SOMETIMES WE ARE UNFAIR TO EACH OTHER.	SA	A	D	SD	NA
21.	WE NEVER LET THINGS PILE UP UNTIL THEY ARE MORE THAN WE CAN HANDLE.	SA	A	D	SD	NA
22.	WE AGREE ABOUT WHO SHOULD DO WHAT IN OUR FAMILY.	SA	A	D	SD	NA
23.	I NEVER KNOW WHAT'S GOING ON IN OUR FAMILY.	SA	A	D	SD	NA

24.	I CAN LET MY FAMILY KNOW WHAT IS BOTHERING ME.	SA	A	D	SD	NA
25.	WE NEVER GET ANGRY IN OUR FAMILY.	SA	A	D	SD	NA
26.	MY FAMILY TRIES TO RUN MY LIFE.	SA	A	D	SD	NA
27.	IF WE DO SOMETHING WRONG, WE DON'T GET A CHANCE TO EXPLAIN.	SA	A	D	SD	NA
28.	WE ARGUE ABOUT HOW MUCH FREEDOM WE SHOULD HAVE TO MAKE OUR OWN DECISIONS.	SA	A	D	SD	NA
29.	MY FAMILY AND I UNDERSTAND EACH OTHER COMPLETELY.	SA	A	D	SD	NA
30.	WE SOMETIMES HURT EACH OTHER'S FEELINGS.	SA	A	D	SD	NA
31.	WHEN THINGS AREN'T GOING WELL IT TAKES TOO LONG TO WORK THEM OUT.	SA	A	D	SD	NA
32.	WE CAN'T RELY ON FAMILY MEMBERS TO DO THEIR PART.	SA	A	D	SD	NA
33.	WE TAKE THE TIME TO LISTEN TO EACH OTHER.	SA	A	D	SD	NA
34.	WHEN SOMEONE IS UPSET, WE DON'T FIND OUT UNTIL MUCH LATER.	SA	A	D	SD	NA
35.	SOMETIMES WE AVOID EACH OTHER.	SA	A	D	SD	NA

36.	WE FEEL CLOSE TO EACH OTHER.	SA	A	D	SD	NA
37.	PUNISHMENTS ARE FAIR IN OUR FAMILY.	SA	A	D	SD	NA
38.	THE RULES IN OUR FAMILY DON'T MAKE SENSE.	SA	A	D	SD	NA
39.	SOME THINGS ABOUT MY FAMILY DON'T ENTIRELY PLEASE ME.	SA	A	D	SD	NA
40.	WE NEVER GET UPSET WITH EACH OTHER.	SA	A	D	SD	NA
41.	WE DEAL WITH OUR PROBLEMS EVEN WHEN THEY'RE SERIOUS.	SA	A	D	SD	NA
42.	ONE FAMILY MEMBER ALWAYS TRIES TO BE THE CENTRE OF ATTENTION.	SA	A	D	SD	NA
43.	MY FAMILY LETS ME HAVE MY SAY, EVEN IF THEY DISAGREE.	SA	A	D	SD	NA
44.	WHEN OUR FAMILY GETS UPSET, WE TAKE TOO LONG TO GET OVER IT.	SA	A	D	SD	NA
45.	WE ALWAYS ADMIT OUR MISTAKES WITHOUT TRYING TO HIDE ANYTHING.	SA	A	D	SD	NA
46.	WE DON'T REALLY TRUST EACH OTHER.	SA	A	D	SD	NA
47.	WE HARDLY EVER DO WHAT IS EXPECTED OF US WITHOUT BEING TOLD.	SA	A	D	SD	NA

48.	WE ARE FREE TO SAY WHAT WE THINK IN OUR FAMILY.	SA	A	D	SD	NA
49.	MY FAMILY IS NOT A PERFECT SUCCESS.	SA	A	D	SD	NA
50.	WE HAVE NEVER LET DOWN ANOTHER FAMILY MEMBER IN ANY WAY.	SA	A	D	SD	NA

ITEM 13

PLAN OF CARE

RE: _____ Client No._____ _____

Period Summarized: _____

1. Goal:

Strategies:

Resolved:

2. Goal:

Strategies:

Resolved:

ITEM 14

DISCHARGE INTERVIEW FORMAT

Date of Interview:_____
Client No.:_____

I. Elderly Person (name)_____

*1. Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4	Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4	Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4	Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2. Degree of Functional Impairment:

Ability to Walk:

Immobile 1	Wheelchair 2	Requires Assistance on Stairs, etc. 3	Independent With Cane, Crutches, or Walker 4	Fully Ambulatory 5

Eating:

Extensive Assistance/ Uncooperative 1	Extensive Assistance/ Cooperative 2	Moderate Assistance/ Cooperative 3	Minor Assistance 4	Without Assistance 5

Dressing:

Has to be dressed/ Uncooperative 1	Has to be dressed/ Cooperative 2	Assistance Only 3	Supervision Only 4	Can dress Self Appropriately 5

*2. Degree of Functional Impairment: (continued)

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3. What is the current status of the elderly person?

Is in same home as at time of assessment ____

Home residence has changed since assessment ____
(Give details of reasons for change)

_____

_____

Is in acute hospital ____
(If hospitalized, give details of Reasons) _____

_____

Is in an Institution ____
(if institutionalized, give details of reasons)

_____

_____

Died ____

*4. Need For Institutionalization:

	Yes	No
Presently	____	____
In Six Months	____	____

Elderly Person (name)_____

*1.2 Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4	Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4	Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4	Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2.2 Degree of Functional Impairment:

Ability to Walk:

Immobile 1	Wheelchair 2	Requires Assistance on Stairs, etc. 3	Independent With Cane, Crutches, or Walker 4	Fully Ambulatory 5

Eating:

Extensive Assistance/ Uncooperative 1	Extensive Assistance/ Cooperative 2	Moderate Assistance/ Cooperative 3	Minor Assistance 4	Without Assistance 5

Dressing:

Has to be dressed/ Uncooperative	Has to be dressed/ Cooperative	Assistance Only	Supervision Only	Can dress Self Appropriately
1	2	3	4	5

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3.2 What is the current status of the elderly person?

Is in same home as at time of assessment ____

Home residence has changed since assessment ____
(Give details of reasons for change)

_____

_____

Is in acute hospital ____
(If hospitalized, give details of Reasons) _____

_____

Is in an Institution ____
(if institutionalized, give details of reasons)

_____

_____

Died ____

*4.2 Need For Institutionalization:

	Yes	No
Presently	____	____
In Six Months	____	____

Elderly Person (name)_____

*1.3 Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4	Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4	Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4	Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2.3 Degree of Functional Impairment:

Ability to Walk:

Immobile 1	Wheelchair 2	Requires Assistance on Stairs, etc. 3	Independent With Cane, Crutches, or Walker 4	Fully Ambulatory 5

Eating:

Extensive Assistance Uncooperative 1	Extensive Assistance/ Cooperative 2	Moderate Assistance/ Cooperative 3	Minor Assistance 4	Without Assistance 5

Dressing:

Has to be dressed/ Uncooperative	Has to be dressed/ Cooperative	Assistance Only	Supervision Only	Can dress Self Appropriately
1	2	3	4	5

*2.3 Degree of Functional Impairment: (continued)

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3.3 What is the current status of the elderly person?

Is in same home as at time of assessment ____

Home residence has changed since assessment ____
(Give details of reasons for change)

_____

_____

Is in acute hospital _____
(If hospitalized, give details of Reasons) _____

_____

Is in an Institution _____
(if institutionalized, give details of reasons)

_____

_____

Died _____

*4.3 Need For Institutionalization:

	Yes	No
Presently	_____	_____
In Six Months	_____	_____

*5. Since intake, have there been any specific events/changes in the family situation of the caregiver(s) affecting their ability to fulfil the caregiving role?

_____

_____

_____

_____

_____

II. Primary Caregiver

*1. What are the needs of the primary caregiver?

(a) _____

_____

(b) _____

_____

(c) _____

_____

(d) _____

_____

2. Is the primary caregiver socially isolated?

3. What roles do neighbours/friends play in caregiving?

4. What specific stresses are faced by the primary caregiver?

III. Family Needs/Dynamics

1. Are family members more involved in caregiving?

2. Have there been any changes in the nature of family relationships (reduction in anxiety and conflict)?

_____

_____

_____

_____

3. Are there any changes in how family decisions are made about the care of the elderly relative(s)?

_____

_____

_____

_____

IV. Knowledge

*1. What is the family's level of knowledge/understanding of the elderly person's(s) condition?

Poor		Average		Excellent
1	2	3	4	5

*2. What is the family's level of knowledge/understanding of caregiving skills?

Poor		Average		Excellent
1	2	3	3	5

*3. What is the level of awareness of community resources on the part of the family?

Poor		Average		Excellent
1	2	3	4	5

What problems/barriers have there been in the family's use of community resources?

_____

_____

_____

_____

*4. Social Worker: Please rate your opinion of how competent the primary caregiver is in the caregiving role.

Not at all competent				Very Competent
1	2	3	4	5

*5. What is the general quality of care provided for the elderly person?

Poor		Average		Excellent
1	2	3	4	5

Comments:

_____

_____

_____

_____

_____

_____

_____

Note: Review initial plan of care and complete information regarding objectives achieved and attach to discharge interview.

ITEM 15

Baycrest Centre
for Geriatric Care

Baycrest Hospital
Baycrest Terrace
Baycrest Day Care Service
The Jewish Home for the Aged
The Joseph E. and Minnie Wagman Centre

(416) 789-5131

Dear Program Participant(s):

As mentioned in your initial interview with Baycrest staff, an evaluation of the Caregiver Project is being conducted by A.R.A. Consultants.

Your participation in this evaluation is very important in that it will help the government to make policy and funding decisions regarding the continuation of programs similar to the Caregivers Project.

In approximately two weeks from now, you will receive a call from Shelley Jamieson who works for A.R.A. Consultants. She will arrange a convenient time to meet with you to discuss your impressions of the Caregiver Project and to ask you some questions concerning your role as a caregiver for your relative. Shelley will also contact you by phone three months later.

Please be reminded that Shelley works for A.R.A. Consultants, collecting evaluation information. Should you require further support or counselling, we encourage you to contact Project staff at Baycrest; 789-5131 Ext. 3077.

Your participation in the Caregiver Project evaluation will be greatly appreciated.

Sincerely,

Sue Weinstein

Sheila Smyth
Director
Caring for the Caregivers Project

Sue Weinstein
A.R.A. Consultants
Project Manager

SS:BJB

3560 Bathurst Street, North York, Ontario M6A 2E1

ITEM 16

Client No._____

Date: _____

Completed by: _____

PRIMARY CAREGIVER QUESTIONNAIRE

FOLLOW-UP I

1. What is your family's current status with the Caring for the Caregivers project? (Do not ask this question, interviewer should just circle #1)

   1 Completed program

2. At present, where is your relative living? (Circle number)

   1 Independently (in their own home or apartment)
   2 Semi-independently (e.g., back and forth between their home and mine)
   3 With me (in my home or theirs)
   4 In a hospital (specify name) _____
   5 Other (specify) _____

3. a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

      1 No
      2 Yes (specify name of institution) _____
        (for how long) _____

   b) Do you believe your relative needs to be in a hospital or institution of some kind? (circle number)

      1 No
      2 Yes (specify name or kind of institution) _____

4. Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	

5. For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

6. Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

7. Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

8. Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

9. What community resources/services did you become aware of as a result of the program?

Name of Service	Did You Use It? (Circle)	Any Problems with Services (for example: availability, cost etc.)
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____

10. As a result of participating in the program, did you learn any new practical caregiving skills? (Circle number)

    1 No

    2 Yes, please describe: _____

    _____

    _____

11. a) What did you find most useful about the counselling session(s) you participated in?

    _____

    _____

    _____

    b) Overall, how useful did you find the counselling session(s)? (Circle appropriate category)

Not at all useful	not very useful	somewhat useful	quite useful	very useful

If you participated in educational workshops, answer the following questions. Otherwise, go to Question 14.

12. (a) What did you find most useful about the educational workshop(s)?

    _____

    _____

    _____

    (b) Overall, how useful were the educational workshops?

not at all useful	not very useful	somewhat useful	quite useful	very useful

If you participated in mutual support groups, answer the following question. Otherwise, go to Question 14.

13. Overall, how useful did you find the mutual support group? (Circle appropriate category)

not at all useful	not very useful	somewhat useful	quite useful	very useful

14. Was the reading material you received from program staff useful? (Circle appropriate category)

Not Useful Somewhat Useful Very Useful Did Not Receive Reading Materials

15. What was the most helpful or useful part of the "Caring for the Caregivers" project for you?

_____

_____

_____

_____

16. What was the least helpful or useful part of the project?

_____

_____

_____

_____

17. Do you feel that participating in this program helped keep your relative in the community and out of an institution? (Circle number)

1 No it did not help

2 Yes it did help

3 Institutionalization not appropriate at this time

Why did participating help or not help? _____

_____

_____

18. Would you recommend the "Caring for the Caregivers" project to other families in similar circumstances to yours? (Circle number)

1 Yes. Why? _____

_____

2 No. Why? _____

_____

3 Maybe. Why? _____

_____

19. What if any changes in the "Caring for the Caregivers" project would have made it more helpful to you and your family? _____

_____

_____

_____

Client No._____

Date: _____

Completed by: _____

PRIMARY CAREGIVER QUESTIONNAIRE

FOLLOW-UP I **(CARING FOR MORE THAN ONE RELATIVE)**

1. What is your family's current status with the Caring for the Caregivers project? (Circle number)

   1 Completed program

Please answer the following questions about the first relative for whom you are providing care.

Relative's Name:_____

2. At present, where is your relative living? (Circle number)

   1 Independently (in their own home or apartment)
   2 Semi-independently (e.g., back and forth between their home and mine)
   3 With me (in my home or theirs)
   4 In a hospital (specify name) _____
   5 Other (specify) _____

3. a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

      1 No
      2 Yes (specify name of institution) _____
        (for how long) _____

   b) Do you believe your relative needs to be in a hospital or institution of some kind? (circle number)

      1 No
      2 Yes (specify name or kind of institution) _____

4. Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	

5. For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

6. Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

7. Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

8. Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

e) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe)					
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

Please answer the following questions about the second relative for whom you are providing care.

Relative's Name:_____

2.2 At present, where is your relative living? (Circle number)

1 Independently (in their own home or apartment)

2 Semi-independently (e.g., back and forth between their home and mine)

3 With me (in my home or theirs)

4 In a hospital (specify name) _____

5 Other (specify) _____

3.2 a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

1 No

2 Yes (specify name of institution) _____

(for how long) _____

b) Do you believe your relative needs to be in a hospital or institution of some kind? (circle number)

1 No

2 Yes (specify name or kind of institution) _____

4.2 Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	

5.2 For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

6.2 Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

7.2 Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

8.2 Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

Please answer the following questions about the third relative form whom you are providing care.

Relative's Name:_____

2.3 At present, where is your relative living? (Circle number)

1 Independently (in their own home or apartment)

2 Semi-independently (e.g., back and forth between their home and mine)

3 With me (in my home or theirs)

4 In a hospital (specify name) _____

5 Other (specify) _____

3.3 a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

1 No

2 Yes (specify name of institution) _____

(for how long) _____

b) Do you believe your relative needs to be in a hospital or institution of some kind? (circle number)

1 No

2 Yes (specify name or kind of institution) _____

4.3 Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	

5.3 For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

6.3 Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

7.3 Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

8.3 Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe)					
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

9. What community resources/services did you become aware of as a result of the program?

Name of Service	Did You Use It? (Circle)	Any Problems with Services (for example: availability, cost etc.)
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____

10. As a result of participating in the program, did you learn any new practical caregiving skills? (Circle number)

    1 No

    2 Yes, please describe: _____

    _____

    _____

11. a) What did you find most useful about the counselling session(s) you participated in?

    _____

    _____

    _____

    b) Overall, how useful did you find the counselling session(s)? (Circle appropriate category)

Not at all useful	not very useful	somewhat useful	quite useful	very useful

If you participated in educational workshops, answer the following questions. Otherwise, go to Question 14.

12. (a) What did you find most useful about the educational workshop(s)?

    _____

    _____

    _____

    (b) Overall, how useful were the educational workshops?

not at all useful	not very useful	somewhat useful	quite useful	very useful

If you participated in mutual support groups, answer the following question. Otherwise, go to Question 14.

13. Overall, how useful did you find the mutual support group? (Circle appropriate category)

not at all useful	not very useful	somewhat useful	quite useful	very useful

14. Was the reading material you received from program staff useful? (Circle appropriate category)

Not Useful Somewhat Useful Very Useful Did Not Receive Reading Material

15. What was the most helpful or useful part of the "Caring for the Caregivers" project for you?

_____

_____

_____

_____

16. What was the least helpful or useful part of the project?

_____

_____

_____

_____

17. Do you feel that participating in this program helped keep your relatives in the community and out of an institution? (Circle number)
a) Response for Relative #1:

1 No it did not help
2 Yes it did help
3 Institutionalization not appropriate at this time

Why did participating help or not help? _____

_____

_____

b) Response for Relative #2:

1 No it did not help
2 Yes it did help
3 Institutionalization not appropriate at this time

Why did participating help or not help? _____

_____

_____

c) Response for Relative #3:

1 No it did not help
2 Yes it did help
3 Institutionalization not appropriate at this time

Why did participating help or not help? _____

_____

_____

18. Would you recommend the "Caring for the Caregivers" project to other families in similar circumstances to yours? (Circle number)

1 Yes. Why? _____

_____

2 No. Why? _____

_____

3 Maybe. Why? _____

_____

19. What if any changes in the "Caring for the Caregivers" project would have made it more helpful to you and your family? _____

_____

_____

_____

ITEM 17

Client No. _____

Date: _____

Completed by: _____

FAMILY MEMBER QUESTIONNAIRE

FOLLOW-UP I

1. Are you currently living with your elderly relative (Circle number)

   1 No

   2 Yes

2. Who is responsible for doing each of the following tasks for your elderly relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself

Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	

3. For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your elderly relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

4. Care of an elderly relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your elderly relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your elderly relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

5. Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your elderly relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your elderly relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your elderly relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your elderly relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

6. Which of the following would you describe as a source of stress for **you** in caring for your elderly relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about elderly relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to elderly relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

7. What community resources/services did you become aware of as a result of the program?

Name of Service	Did You Use It? (Circle)	Any Problems with Services (for example: availability, cost etc.)
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____

8. As a result of participating in the program, did you learn any new practical caregiving skills? (Circle number)

   1 No

   2 Yes, please describe: _____

   _____

   _____

9. a) What did you find most useful about the counselling session(s) you participated in?

   _____

   _____

   _____

   b) Overall, how useful did you find the counselling session(s)? (Circle appropriate category)

Not at all useful	not very useful	somewhat useful	quite useful	very useful

If you participated in educational workshops, answer the following questions. Otherwise, go to Question 12.

10. (a) What did you find most useful about the educational workshop(s)?

   _____

   _____

   _____

   (b) Overall, how useful were the educational workshops?

not at all useful	not very useful	somewhat useful	quite useful	very useful

If you participated in mutual support groups, answer the following question. Otherwise, go to Question 12.

11. Overall, how useful did you find the mutual support group? (Circle appropriate category)

not at all useful	not very useful	somewhat useful	quite useful	very useful

12. Was the reading material you received from program staff useful? (Circle appropriate category)

Not Useful Somewhat Useful Very Useful Did Not Receive Reading Materials

13. What was the most helpful or useful part of the "Caring for the Caregivers" project for you?

_____

_____

_____

_____

14. What was the least helpful or useful part of the project?

_____

_____

_____

_____

15. Do you feel that participating in this program helped keep your relative in the community and out of an institution? (Circle number)

1 No it did not help

2 Yes it did help

3 Institutionalization not appropriate at this time

Why did participating help or not help? _____

_____

_____

16. Would you recommend the "Caring for the Caregivers" project to other families in similar circumstances to yours? (Circle number)

1 Yes. Why? _____

_____

2 No. Why? _____

_____

3 Maybe. Why? _____

_____

17. What if any changes in the "Caring for the Caregivers" project would have made it more helpful to you and your family? _____

_____

_____

_____

Client No._____

Date: _____

Completed by: _____

FAMILY MEMBER QUESTIONNAIRE

FOLLOW-UP I **(CARING FOR MORE THAN ONE RELATIVE)**

Please answer the following questions about the first relative for whom you are providing care.

Relative's Name:_____

1. Are you currently living with your elderly relative (Circle number)

   1 No

   2 Yes

2. Who is responsible for doing each of the following tasks for your elderly relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself

Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	

3. For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your elderly relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

4. Care of an elderly relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your elderly relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your elderly relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

5. Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your elderly relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your elderly relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your elderly relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your elderly relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

6. Which of the following would you describe as a source of stress for **you** in caring for your elderly relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about elderly relative's future (e.g., relative's	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to elderly relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

Please answer the following questions about the second relative for whom you are providing care.

Relative's Name:_____

1.2 Are you currently living with your elderly relative (Circle number)

1 No

2 Yes

2.2 Who is responsible for doing each of the following tasks for your elderly relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself

Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Other (describe) _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	

3. For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your elderly relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

4. Care of an elderly relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your elderly relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your elderly relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

5. Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your elderly relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your elderly relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your elderly relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your elderly relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

4.2 Care of an elderly relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your elderly relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your elderly relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

5.2 Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your elderly relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your elderly relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your elderly relative?

no cooperation at all	not very much cooperation	some cooperation	quite a lot of cooperation	a great deal of cooperation

d) How much conflict is there in your family over the care of your elderly relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

6.2 Which of the following would you describe as a source of stress for **you** in caring for your elderly relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about elderly relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to elderly relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe)					
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

Please answer the following questions about the third relative for whom you are providing care.

Relative's Name:_____

1.3 Are you currently living with your elderly relative (Circle number)

1 No

2 Yes

2.3 Who is responsible for doing each of the following tasks for your elderly relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself

Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	

3.3 For each of the tasks listed below, indicate on average, how many hours each week **you** spend doing the task for your elderly relative. (Write in the number of hours. If none, write 0.)

	Number of Hours per Week
Telephone check-up	_____
Visits/companionship	_____
Shopping/errands for relative	_____
Meals (preparation and delivery)	_____
Attending medical appointments with your relative	_____
Transportation	_____
Household chores	_____
Physical (e.g., dressing, feeding, bathing)	_____
Nursing (e.g., changing dressings, giving medications)	_____
Other (describe)	
_____	_____
_____	_____
_____	_____

4.3 Care of an elderly relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your elderly relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your elderly relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

5.3 Circle the appropriate category for each of the questions below to indicate your answer.

a) How knowledgeable do you feel about your elderly relative's state of health?

not at all knowledge-able	not very knowledge-able	somewhat knowledge-able	quite knowledge-able	completely knowledge-able

b) Do you feel you have the caregiving skills you need to look after your elderly relative?

not at all skilled	not very skilled	somewhat skilled	quite skilled	completely skilled

c) How much cooperation is there in your family over the care of your elderly relative?

no coopera-tion at all	not very much coop-eration	some coop-eration	quite a lot of co-operation	a great deal of cooperation

d) How much conflict is there in your family over the care of your elderly relative?

a great deal of conflict	quite a lot of conflict	some conflict	not very much conflict	no conflict at all

Sources of Stress

6.3 Which of the following would you describe as a source of stress for **you** in caring for your elderly relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress
h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about elderly relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress

l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to elderly relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with elderly relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

7. What community resources/services did you become aware of as a result of the program?

Name of Service	Did You Use It? (Circle)	Any Problems with Services (for example: availability, cost etc.)
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____
_____	NO YES	_____

8. As a result of participating in the program, did you learn any new practical caregiving skills? (Circle number)

   1 No

   2 Yes, please describe: _____

   _____

   _____

9. a) What did you find most useful about the counselling session(s) you participated in?

   _____

   _____

   _____

   b) Overall, how useful did you find the counselling session(s)? (Circle appropriate category)

Not at all useful	not very useful	somewhat useful	quite useful	very useful

If you participated in educational workshops, answer the following questions. Otherwise, go to Question 12.

10. (a) What did you find most useful about the educational workshop(s)?

   _____

   _____

   _____

   (b) Overall, how useful were the educational workshops?

not at all useful	not very useful	somewhat useful	quite useful	very useful

If you participated in mutual support groups, answer the following question. Otherwise, go to Question 12.

11. Overall, how useful did you find the mutual support group? (Circle appropriate category)

not at all useful	not very useful	somewhat useful	quite useful	very useful

12. Was the reading material you received from program staff useful? (Circle appropriate category)

Not Useful Somewhat Useful Very Useful Did Not Receive Reading Material

13. What was the most helpful or useful part of the "Caring for the Caregivers" project for you?

_____

_____

_____

_____

14. What was the least helpful or useful part of the project?

_____

_____

_____

_____

15. Do you feel that participating in this program helped keep your relative in the community and out of an institution? (Circle number)

1 No it did not help

2 Yes it did help

Why did participating help or not help? _____

_____

_____

16. Would you recommend the "Caring for the Caregivers" project to other families in similar circumstances to yours? (Circle number)

1 Yes. Why? _____

_____

2 No. Why? _____

_____

3 Maybe. Why? _____

_____

17. What if any changes in the "Caring for the Caregivers" project would have made it more helpful to you and your family? _____

_____

_____

_____

ITEM 18

Client No. _____

Date: _____

Completed by: _____

PRIMARY CAREGIVER QUESTIONNAIRE

FOLLOW-UP II

1. At present, where is your relative living? (Circle number)

   1 Independently (in their own home or apartment)
   2 Semi-independently (e.g., back and forth between their home and mine)
   3 With me (in my home or theirs)
   4 In a hospital (specify name) _____
   5 Other (specify) _____

2. a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

   1 No
   2 Yes (specify name of institution) _____
   (for how long) _____

   b) Do you believe your relative needs to be in a hospital or institution of some kind? (Circle number)

   1 No
   2 Yes (specify name of institution) _____

3. In the last three months, has anything happened to you, or other family members that has affected your ability to fulfil your caregiving role? (Explain) _____

_____

_____

_____

_____

4. Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	

5. Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

Sources of Stress

6. Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming	major stress	moderate stress	minor stress	not a stress

h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe)					
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

7. What community resources/services did you use in the past 3 months

Name of Service	**Any Problems With Services (for example, availability, cost, etc.)**
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

If you took part in a mutual support group, answer the following questions.

8. In the past 3 months how often did you:

(a) Have telephone contact with any of the group members? (Circle number)

1 Once a week or more
2 Once or twice a month
3 Once every 2 - 3 months
4 Not at all
____ Total number of contacts

(b) Meet with one or more of the group members socially? (Circle number)

1 Once a week or more
2 Once or twice a month
3 Once every 2 - 3 months
4 Not at all
____ Total number of contacts

(c) Meet as a self-help group with some or all of the group members? (Circle number)

1 Once a week or more
2 Once or twice a month
3 Once every 2 - 3 months
4 Not at all
____ Total number of contacts

Client No._____

Date: _____

Completed by: _____

PRIMARY CAREGIVER QUESTIONNAIRE

FOLLOW-UP II

(CARING FOR MORE THAN ONE RELATIVE)

Please answer the following questions about the first relative for whom you are providing care.

1. At present, where is your relative living? (Circle number)

   1 Independently (i.e. their own home or apartment)

   2 Semi-independently (e.g., back and forth between their home and mine)

   3 With me (in my home or theirs)

   4 In a hospital (specify name) _____

   5 Other (specify) _____

2. a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

      1 No

      2 Yes (specify name of institution) _____

      (for how long) _____

   b) Do you believe your relative needs to be in a hospital or institution of some kind? (Circle number)

      1 No

      2 Yes (specify name of institution) _____

3. Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility (specify relationship; sister, nurse) _____ _____	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility (specify relationship; sister, nurse _____) _____)	

4. Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

Sources of Stress

5. Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feeling of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress

h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

Please answer the following questions about the second relative for whom you are providing care.

Relative's Name: _____

1.2 At present, where is your relative living? (Circle number)

1 Independently (in their own home or apartment)

2 Semi-independently (e.g., back and forth between their home and mine)

3 With me (in my home or theirs)

4 In a hospital (specify name) _____

5 Other (specify) _____

2.2 a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

1 No

2 Yes (specify name of institution) _____

(for how long) _____

b) Do you believe your relative needs to be in a hospital or institution of some kind? (Circle number)

1 No

2 Yes (specify name of institution) _____

3.2 Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse) _____ _____	Someone else's responsibility alone (specify relationship; sister, nurse) _____ _____	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	

4.2 Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

Sources of Stress

5.2 Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress

h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe)					
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

Please answer the following questions about the third relative for whom you are providing care.

Relative's Name: _____

1.3 At present, where is your relative living? (Circle number)

1 Independently (in their own home or apartment)

2 Semi-independently (e.g., back and forth between their home and mine)

3 With me (in my home or theirs)

4 In a hospital (specify name) _____

5 Other (specify) _____

2.3 a) Has your relative been placed in a hospital or any other institution within the last six months? (Circle number)

1 No

2 Yes (specify name of institution) _____

(for how long) _____

b) Do you believe your relative needs to be in a hospital or institution of some kind? (Circle number)

1 No

2 Yes (specify name of institution) _____

3.3 Who is responsible for doing each of the following tasks for your relative? (Circle appropriate category for each task).

Telephone Check-Up	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Task is not Required
Visits/ companion-ship	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Task is not Required
Shopping/ errands for relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Meals (preparation and delivery)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Attending medical appointments with relative	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself

Transportation	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Household chores	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Physical (e.g. dressing, feeding, bathing)	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Nursing (e.g. changing dressings, giving medication	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	Relative does this him/herself
Other (describe) _____ _____ _____ _____ _____	My responsibility alone	Mainly my responsibility but someone else takes over occasionally (when I am away, sick)	Responsibility is shared by others (specify relationship; sister, nurse _____) _____)	Someone else's responsibility alone (specify relationship; sister, nurse _____) _____)	

4.3 Care of a relative can be both rewarding and stressful. Circle the appropriate category to indicate your answers to each of the following questions.

a) Overall, how rewarding is it for you to care for your relative?

very unrewarding	unrewarding	somewhat rewarding	rewarding	very rewarding

b) Overall, how stressful is it for you to care for your relative?

overwhelming stress	major stress	moderate stress	minor stress	no stress

Sources of Stress

5.3 Which of the following would you describe as a source of stress for **you** in caring for your relative? (Circle a level of stress for each source of stress listed below)

a) The financial costs of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
b) The worry/feelings of responsibility of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
c) The amount of time spent in caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
d) The physical demands of caregiving	over-whelming stress	major stress	moderate stress	minor stress	not a stress
e) Difficulty in meeting needs of own family (spouse, children)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
f) Limitations on living my own life (e.g., work, leisure, social life, etc.)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
g) Lack of privacy	over-whelming stress	major stress	moderate stress	minor stress	not a stress

h) Problems in finding/ arranging services (e.g. Meals on Wheels, visiting homemaker)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
i) Concern about present health of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
j) Lack of knowledge/ information about health condition of relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
k) Concern about relative's future (e.g., relative's health)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
l) Concern about own future (own health, things getting worse)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
m) Conflict/problems with other family members over care	over-whelming stress	major stress	moderate stress	minor stress	not a stress
n) Difficulty in giving advice to relative or having advice accepted	over-whelming stress	major stress	moderate stress	minor stress	not a stress
o) Conflict/problems with relative	over-whelming stress	major stress	moderate stress	minor stress	not a stress
p) Having no one to share worries/ concerns with	over-whelming stress	major stress	moderate stress	minor stress	not a stress
q) Problems with layout of the house (e.g., stairs)	over-whelming stress	major stress	moderate stress	minor stress	not a stress
r) Other (please describe) _____	over-whelming stress	major stress	moderate stress	minor stress	not a stress
_____	over-whelming stress	major stress	moderate stress	minor stress	not a stress

6. In the last three months, has anything happened to you, or other family members that has affected your ability to fulfil your caregiving role? (Explain) _____

_____

_____

_____

_____

7. What community resources/services did you use in the past 3 months

Name of Service	**Any Problems With Services (for example, availability, cost, etc.)**
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

If you took part in a mutual support group, answer the following questions.

8. In the past 3 months - how often did you:

(a) Have telephone contact with any of the group members? (Circle number)

1 Once a week or more
2 Once or twice a month
3 Once every 2 - 3 months
4 Not at all
____ Total number of contacts

(b) Meet with one or more of the group members socially? (Circle number)

1 Once a week or more
2 Once or twice a month
3 Once every 2 - 3 months
4 Not at all
____ Total number of contacts

(c) Meet as a self-help group with some or all of the group members? (Circle number)

1 Once a week or more

2 Once or twice a month

3 Once every 2 - 3 months

4 Not at all

____ Total number of contacts

ITEM 19

Client No._____

FOLLOW-UP III **INTERVIEW FORMAT**

Date of Interview:_____

I. **Elderly Person (name)**_____

*1. Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4	Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4	Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4	Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2. Degree of Functional Impairment:

Ability to Walk:

Immobile 1	Wheelchair 2	Requires Assistance on Stairs, etc. 3	Independent With Cane,or Crutches, Walker 4	Fully Ambulatory 5

Eating:

Extensive Assistance/ Uncooperative 1	Extensive Assistance/ Cooperative 2	Moderate Assistance/ Cooperative 3	Minor Assistance 4	Without Assistance 5

Dressing:

Has to be dressed/ Uncooperative 1	Has to be dressed/ Cooperative 2	Assistance Only 3	Supervision Only 4	Can dress Self Appropriately 5

*2. Degree of Functional Impairment: (continued)

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3. What is the current status of the elderly person?

Is in same home as at time of assessment ____

Home residence has changed since assessment ____
(Give details of reasons for change)

_____

_____

Is in acute hospital
(If hospitalized, give details of Reasons) _____

_____

Is in an Institution
(if institutionalized, give details of reasons)

_____

_____

Died

*4. Need For Institutionalization:

	Yes	No
Presently	____	____
In Six Months	____	____

Elderly Person (name)_____

*1.2 Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4	Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4	Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4	Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2.2 Degree of Functional Impairment:

Ability to Walk:

Immobile 1	Wheelchair 2	Requires Assistance on Stairs, etc. 3	Independent With Cane, or Crutches, Walker 4	Fully Ambulatory 5

Eating:

Extensive Assistance/ Uncooperative 1	Extensive Assistance/ Cooperative 2	Moderate Assistance/ Cooperative 3	Minor Assistance 4	Without Assistance 5

*2.2 Degree of Functional Impairment: (continued)

Dressing:

Has to be dressed/ Uncooperative	Has to be dressed/ Cooperative	Assistance Only	Supervision Only	Can dress Self Appropriately
1	2	3	4	5

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3.2 What is the current status of the elderly person?

Is in same home as at time of assessment ____

Home residence has changed since assessment ____
(Give details of reasons for change)

_____

_____

Is in acute hospital ____
(If hospitalized, give details of Reasons) _____

_____

*3.2 What is the current status of the elderly person? (cont'd)

Is in an Institution _____
(if institutionalized, give details of reasons)

_____

_____

Died _____

*4.2 Need For Institutionalization:

	Yes	No
Presently	_____	_____
In Six Months	_____	_____

Elderly Person (name)_____

*1.3 Level of Cognitive Impairment:

Is he/she repetitive?	Very Repetitive 1	2	Somewhat Repetitive 3	4	Not at all Repetitive 5
Is he/she forgetful?	Very Forgetful 1	2	Somewhat Forgetful 3	4	Not at all Forgetful 5
Is he/she disoriented to place and person?	Very Disoriented 1	2	Somewhat Disoriented 3	4	Not at all Disoriented 5

Mental Ability to Manage Affairs:

Completely Unable to Comprehend Affairs 1	Unreliable due to Intermittent Confusion 2	Capable of Handling only Minor Daily Business 3	Capable but Needs some Guidance 4	Completely Capable in all Affairs 5

*2.3 Degree of Functional Impairment:

Ability to Walk:

Immobile 1	Wheelchair 2	Requires Assistance on Stairs, etc. 3	Independent With Cane, or Crutches, Walker 4	Fully Ambulatory 5

*2.3 Degree of Functional Impairment: (cont'd)

Eating:

Extensive Assistance/ Uncooperative	Extensive Assistance/ Cooperative	Moderate Assistance/ Cooperative	Minor Assistance	Without Assistance
1	2	3	4	5

Dressing:

Has to be dressed/ Uncooperative	Has to be dressed/ Cooperative	Assistance Only	Supervision Only	Can dress Self Appropriately
1	2	3	4	5

Bathing/washing:

Unable/ Uncooperative	Unable/ Cooperative	Assistance In and Out Of Tub	Supervision Only	Without Assistance
1	2	3	4	5

Household chores:

Unable to do Any chores	Light chores With Assistance	Light chores Without Assistance	Heavier chores With Assistance	All chores Without Assistance
1	2	3	4	5

Getting Out of House:

Unable to Get out	Specialized Transportation (wheelchair, etc)	Assistance With Public Transportation	Supervision Only on public Transportation	Can use public Transportation /Drives car
1	2	3	4	5

Shopping:

Unable to Shop	Extensive Assistance	Minor Assistance	Supervision Only	Without Assistance/ Supervision
1	2	3	4	5

*3.3 What is the current status of the elderly person?

Is in same home as at time of assessment ____

Home residence has changed since assessment ____
(Give details of reasons for change)

_____

_____

*3.3 What is the current status of the elderly person? (cont'd)

Is in acute hospital _____
(If hospitalized, give details of Reasons) _____

_____

Is in an Institution _____
(if institutionalized, give details of reasons)

_____

_____

Died _____

*4.3 Need For Institutionalization:

	Yes	No
Presently	_____	_____
In Six Months	_____	_____

*5. In the last three months, have there been any specific events/changes in the family situation of the caregiver(s) affecting their ability to fulfil the caregiving role?

_____

_____

_____

_____

_____

6. Are other family members more involved in caregiving?

_____

_____

_____

_____

_____

*7. What is the general quality of care provided for the elderly person?

Poor		Average		Excellent
1	2	3	4	5

8. New Problems/Additional Plans

Additional Notes: